



## GLOBAL HD-CAB COALITION PARTNER AGREEMENT

### 1. Mission

The coalition's main mission is to represent the voice of the global HD community and provide HD community experience to regulators, industry, researchers and governing bodies. HD-CAB is an instrument to facilitate patient-oriented research and clinical trials as well as fair processes to make treatment accessible for all patients. HD-CAB will provide the unique expertise of living with HD to stakeholders relevant for therapeutic development.

### 2. Name

The coalition will be named Global HD-CAB (Huntington Disease - Community Advisory Board)

### 3. Goals

Global HD-CAB will:

- Coordinate with pharmaceuticals/academic groups/foundations with our global advisory team to ensure research progression is done aligned with the needs of the HD community
- Advocate with governing bodies globally to make drugs accessible to the HD community

### 4. Guiding principles

Global HD-CAB will be an independent member of Eurordis EURO-CAB and follow the principles in this agreement. (Appendix 1)

### 5. Founding Partners

The coalition partners are European Huntington Association (EHA), International Huntington Association (IHA) and Huntington Disease Youth Organisation (HDYO).

#### Admission of Partners

The Management Board can admit new Partners as they find useful and promoting for the mission of Global HD-CAB.

### 6. Leaving the coalition

At any time, a Partner may choose to leave the Coalition, by providing written notice to the Global HD-CAB chair. Once an organization ceases to be a Partner, that organization will promptly cease any use of the Global HD-CAB marks and will no longer hold itself out as a Global HD-CAB partner.

### 7. Termination of partnership

Two thirds of the Management board can exclude a partner with a cause. Cause includes, but is not limited to, violation of the basic rules in this agreement.

### 8. Identification as Global HD-CAB coalition partner

Partners can identify themselves as partners of Global HD-CAB in both their internal and public efforts, including public statements, publications, websites and grant applications.

## 9. Public statements

Partners may not make any statement on policy, partisan politics or practice that may be interpreted as a statement from any other Partner of the Coalition as a whole. Partners will not use the Global HD-CAB Marks (defined below) in such a way as to give the impression that any other Partner of the Coalition as a whole is making any statement on policy, partisan politics or practice.

## 10. Use by Partners of the Global HD-CAB Name and Logo

Partners may use the Global HD-CAB logo, name and other designs (collectively, the Global HD-CAB marks) in accordance with this agreement. In order to protect and maximize the value of the Global HD-CAB Marks to all, Partners will comply with the following provisions:

- **Form:** Partners will only use the Global HD-CAB marks in the form provided to them by Global HD-CAB. Partners will not combine the Global HD-CAB Marks with any other trademark, word, symbol, letter, design, or mark.
- **No confusion:** Partners will not use the Global HD-CAB marks as part of their organizational or service name or Internet domain or style. Partners will not use the Global HD-CAB marks in such a way as to give the impression that the Global HD-CAB marks are their property.
- **No Disparagement:** Partners will not use any Global HD-CAB marks in connection with any activity that disparages Global HD-CAB, damages the goodwill associated with Global HD-CAB or is in a context that is otherwise inconsistent with the coalitions values and mission.

## 11. Management

Each partner appoints one person to represent their respective association in the Management board.

The partners will share the responsibility of chairing the Management Board by having the chair rotate among them in the following order: EHA, IHA, HDYO.

A Partner can refrain from taking on the chair responsibilities for any reason. The chair then goes to next Partner in accordance with the above listed order.

The chairperson serves for a period of 2 years.

Management board meets at a frequency they find adequate, but at a minimum of 3 annual meetings, in person or online.

The CAB members appoint a representative to sit in the Management board for a period of 2 years

Management board ensure that the Coalition is fulfilling its mission and is growing to be a stronger and more influential group. To that end the Management board is responsible for:

- Making decisions about Partnership
- Oversee the Global HD-CAB daily governance
- Supporting the Operational team in strengthening the Coalition mission, strategic plan, programs and resource development.

## **12. Management Board Decision-making**

Except as where otherwise provided for in this Agreement, the Management Board will operate by consensus. Granting “consent” means that the Partner can live with the decision and support its implementation. Consensus also means that Partners are committed to a process of decision-making that is inclusive, transparent and reasoned.

If consensus cannot be reached, all Partners will seek in good faith to find alternatives that satisfy the greatest number of Partners and interests possible. Should the Partners reach an impasse after good faith deliberations, the Management chair will ask the Advisory Board Members to vote on the issue and the decision will be made based on simple majority of the votes.

## **13. Operational team**

The Management board establish an Operational Team as they find feasible and necessary to run the daily activities and share responsibilities within the coalition. The operations comply to the standards and procedures set in the EURO CAB agreement.

### **14. Core operations for the Operational Team:**

- Recruitment, training and coordination of the Advisory board members
- Information and marketing of the coalition existence and value
- Contact with industry and other research stakeholders
- Organization of Advisory Boards

## **15. Advisory Team members**

The partners recruit members to the team jointly. The Management Board can change the number and criteria, but at the initiation of this initiative we will follow the below mentioned criteria.

- Geographical distribution: Europe 6, North America 6, Asia 3, Australia/NZ 3, South America 3, Africa 2, Arabic countries 2.
- Family relation: 30-40% gene positive, 30-40% at-risk or gene negative, 20-30% partner/spouse
- 50% between the age of 18 and 40
- Qualifications of Advisory Team Members
- HD family member
- Good English skills on the minimum level of B2/C1
- Capability and availability to commit to the advisory board training and consultations.

## **16. Advisory Team Member Term**

The team members can serve of a total of 3 years – 1/3 of the members rotate every year.

## **17. Financial Management**

### **Funding sources**

HD-CAB International will fund its activities from the fees paid by industry partners consulting the Advisory Team.

Other funding sources may be considered as the Management board finds adequate.

## **18. Audit and financial reports**

The Operational team/coordinator is responsible for keeping accounts and report every six months to the Management Board or anytime on request from one of the Partners.