

# BYLAWS OF THE INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH

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## **I. NAME AND ADDRESS**

1. The name of the organisation is International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR), hereafter referred to as the “Clearinghouse”.
2. The organisation’s principal office is located at the International Center on Birth Defects – ICBD, Rm 2W401 – Division of Medical Genetics, Department of Pediatrics, University of Utah, 295 Chipeta Way, Salt Lake City UT 84108, USA

## **II. ORGANISATION**

1. The Clearinghouse is a domestic not-for-profit corporation, incorporated in the state of Georgia (Secretary of State) and exempt from Federal Income Tax under section 501(c) (3) of the Internal Revenue Code in the United States.
2. The Clearinghouse is a non-governmental organisation (NGO) in an official relationship with the World Health Organisation (WHO).

## **III. PRINCIPLES**

1. The strategic priority of the Clearinghouse is to conduct worldwide surveillance of birth defects;
2. The scope of the Clearinghouse includes fetal and childhood conditions caused by factors before or during pregnancy;
3. The Clearinghouse will engage in educational activities (either for professionals or for the general population) in the field of birth defects and promote the creation of groups for technical discussion;
4. The Clearinghouse will promote guidelines and definitions for conducting surveillance of birth defects;
5. The Clearinghouse will coordinate research activities with the Members, Affiliates and other collaborators.
6. The Clearinghouse will coordinate global prevention and awareness efforts across organizations; and
7. The Clearinghouse will maintain appropriate standards for confidentiality and security of data.

## **IV. OBJECTIVES AND FUNCTIONS**

The objectives of the Clearinghouse are to prevent birth defects and ameliorate their consequences.

In order to achieve these objectives, the Clearinghouse will:

1. Operate an international program for regular exchange of information amongst its members on birth defects in populations covered by the members’ surveillance and research programs;
2. Advocate for the surveillance, research and prevention of birth defects;
3. Conduct and collaborate in joint epidemiological studies on the patterns and causes of birth defects;
4. Increase scientific knowledge on birth defects and their causes in order to promote their prevention (primary, secondary, tertiary);
5. Provide training for effective ascertainment of these conditions and advance the skills in surveillance and research;
6. Collaborate in the education for the public to increase awareness and knowledge of birth defects and their causes, in order to promote their prevention;
7. Conduct assessments of preventive and therapeutic interventions for birth defects;
8. Provide international statements / declarations as needed on issues concerning birth defects;
9. Collaborate with other organizations in the field for better achievement of its objectives.

## **V. PROGRAM MEMBERS**

### **A. Qualifications and Criteria**

1. Members are programs which are engaged in the systematic collection and analysis of data for surveillance and research on birth defects.
2. These programs must also be capable of undertaking epidemiological investigations of birth defects.
3. A Member must be a surveillance program that has collected baseline data on the occurrence of birth defects for at least two years using its current ongoing method of surveillance and is able to provide annual data to the Clearinghouse.
4. Member programs will be able to carry out systematic data collection and use these data for public health action. Public health action includes comparing prevalence rates, advocacy, policy development, conducting epidemiological studies of causes and consequences of birth defects, assessment of preventive or therapeutic interventions, as well as prenatal or postnatal screening, and interacting with the public, research institutions, hospitals, healthcare personnel and relevant government agencies.
5. When a program applies to be a Member of the Clearinghouse and the data overlaps with a pre-existing Member (full overlapping will not be accepted unless a different methodology is offered, i.e. population-based vs. hospital-based), it will be accepted to be a Member if it fulfills the criteria to be a Member, BUT it has to observe some rules:
  - a. The problem of overlapping must be solved for joint studies in which both overlapping programs wish to participate, and the duty to avoid any overlap of data is the requirement of the Principal Investigator(s) (to decide on whether the overlapping is relevant for the study or not) to the program, depending on the specific characteristics of the joint study. If the overlapping could not be solved, the participation of the new program in such joint studies would not be possible.
  - b. Also, the description of the new program for ICBDSR's website, for the Annual Report, or any other space where the Clearinghouse members are described, must include details on the issue of overlapping and how it is solved.
  - c. Data on birth defects prevalence in the new program can be included in the Annual Report, even if there is overlapping with a pre-existing Member, given that the new program description must include details on the issue of overlapping and its solving.
6. Only a Program Director or their representative from a Program Member, which is current with dues payment or has an approved exemption request (hereafter referred to as an "Eligible Program Member") can be nominated to serve on the Executive Committee or other Standing Committees.

### **B. Representation**

Each Member will designate a Program Director and optionally an Associate Program Director to be the principal liaison with the Clearinghouse.

### **C. Responsibilities**

Members are required to:

1. Accept these Bylaws;
2. Submit annual data and an annual report of activities in the prescribed form by the deadline;
3. Serve on committees as designated at the Annual Business Meeting or by the Executive Committee;
4. Respond to specific requests from the Clearinghouse and participate in specific studies if possible;
5. Provide relevant information with respect to their activities (especially surveillance) for inclusion in newsletters and reports of the Clearinghouse;
6. Communicate any relevant change in their programs that could affect the surveillance and interpretation of data.

#### **D. Voting Rights**

Subject to *Section X paragraph C1, and Section XII paragraph A*, each Member program shall have one vote at the Annual Business Meetings or when voting by other (postal or electronic) means, as shall be specified by the Executive Committee.

#### **E. Membership Application**

1. Programs that meet the criteria for membership may apply using the Application for Membership form (see ICBDSR's website).
2. The application will be considered by the Executive Committee, who will then send a written recommendation to the Program Directors of all Members before the Annual Business Meeting.
3. Following a presentation by an applicant or his/her designee at the Annual Business Meeting, Members will discuss and vote on the program's application.
4. An affirmative vote by at least two-thirds of the votes (cast at the Annual Business Meeting or by a proxy) is required for a successful application. In the event of a successful application, the applicant shall become a Member from the conclusion of the Annual Business Meeting at which its application was considered.

### **VI. AFFILIATE MEMBERS**

1. There will be a membership category called "Affiliates".
2. Individuals, or organisations may apply or be invited to become Affiliates. Acceptance is at the discretion of the Executive Committee. The Executive Committee will be responsible to review the new applications and make recommendations to the members at the Annual Business Meeting. ICBDSR members will vote on each new Affiliate member application at the Annual Business Meeting.
3. Affiliates must accept these Bylaws.
4. Affiliates will not have voting rights.
5. An annual membership fee of \$500 will be assessed to all for-profit organisations or companies.
6. At the discretion of the Executive Committee, Affiliates may be required to pay annual dues.
7. At the discretion of the Executive Committee, Affiliates may attend or participate in the Annual Scientific and Business Meetings.
8. Affiliates are encouraged to participate in Clearinghouse's projects or activities.
9. Affiliates will renew their membership every 3 years and document their Clearinghouse activities. Renewal applications will be reviewed and approved by the Executive Committee.

### **VII. EXECUTIVE COMMITTEE**

#### **A. Duties of the Executive Committee**

The Executive Committee shall:

1. Carry out all assignments as described in the Bylaws and given it at the Annual Business Meeting;
2. Prepare an annual budget for the year to come and updated budget for the current year, for approval at the Annual Business Meeting;
3. Undertake commitments consistent with the purposes and objectives of the Clearinghouse and make disbursements in accordance with the approved budget;
4. Represent the Clearinghouse in relations with other organisations, as directed by the members at the Annual Business Meeting;
5. Evaluate the activity of the individual Members;
6. Initiate investigatory measures necessitated by the monitoring activities during the year;
7. Give guidelines for the functions of the Clearinghouse.

**B. Number of Officers and Titles**

There shall be three officers:

1. Executive Chair
2. Executive Vice Chair
3. Secretary/Treasurer

**C. Eligibility**

The Executive Chair, Executive Vice Chair and Secretary/Treasurer shall be selected from among Program Directors or their representatives from Eligible Program Members.

**D. Nominating Procedure**

The Nominating Committee shall nominate a minimum of one willing candidate for each officer position from among Program Directors or their representatives from Eligible Program Members. Program Directors or their representatives shall be notified of nominations by the Nominating Committee not less than 60 days prior to the Annual Business Meeting.

**E. Selection Procedure**

The Executive Chair, Executive Vice Chair and Secretary/Treasurer are elected by the majority of votes cast, including proxy votes, at each Annual Business Meeting.

**F. Terms of Office**

1. Each officer shall serve a two year term, beginning at the conclusion of the Annual Business Meeting at which he/she is elected. Confirmation of the second year of the officer's term will be voted upon at the next succeeding Annual Business Meeting. In case of voting by other (postal or electronic) means (with reference to *Section XI*) the new officers shall serve from the date of their election. The previous officers serve until the election date, taking care of the final election procedure and the officer's duties.
2. No officer shall serve more than two consecutive years in the office to which they are elected and no longer than six consecutive years on the Executive Committee. There must be a two-year interval between successive terms in the same office or serving on the Executive Committee after six consecutive years.

**G. Officer Duties**

1. The Executive Chair calls meetings and presides over the Executive Committee, prepares the agenda for the Executive, Annual Business and Scientific Meetings and chairs these meetings. The Executive Chair shall propose at the Annual Business Meeting new committees to be created, as he/she deems necessary, appoint Committee Chairs and Committee members, except for the Executive and Nominating Committee. The Executive Chair shall appoint *working groups* as he/she deems necessary. The Executive Chair shall have a casting vote in any decision of the Executive Committee.
2. The Executive Vice Chair assists the Executive Chair as requested and presides at Executive, Annual Business and Scientific Meetings in the absence of the Executive Chair, evaluates new membership application(s) and notifies the applicant(s) about the decision. The Executive Vice Chair is in charge of organizing the Scientific Sessions of the Annual Meetings.
3. The Secretary/Treasurer keeps adequate, legible and accurate records pertaining to membership of the Clearinghouse, prepares and circulates minutes of the Executive Committee meetings, Business meetings and selected sessions of the Scientific Meetings. He/she is responsible for the voting procedures. The Secretary/Treasurer manages the budget, keeps the financial records and presents audited (by the Internal Audit Committee, as defined in Section VIII, paragraph A) financial reports of the activities of the Clearinghouse, at the Annual Business Meeting.

## **H. Vacancies**

In the absence of the Executive Chair, the Executive Vice Chair will assume the responsibilities of the Executive Chair. Any officer vacancy that occurs between Annual Business Meetings shall be filled through appointment by the Executive Committee and will be valid until the next Annual Business Meeting.

## **VIII. OTHER COMMITTEES**

### **A. Standing Committees**

1. Nominating
2. Annual Scientific Meeting
3. Awards
4. Internal Audit (financial issues)

### **B. Selection Procedures and Terms for Standing Committees**

1. Nominating Committee:
  - a. Duties of the Nominating Committee**

The Nominating Committee shall nominate a minimum of one willing candidate for each officer position from among Program Directors or their representatives from Eligible Program Members. Program Directors or their representatives shall be notified of nominations by the Nominating Committee not less than 60 days prior to the Annual Business Meeting.
  - b. Number of Members**

There will be no chair for this committee. The committee shall be composed of four members: the ICBD Director; Immediate Past Executive Chair; and two Program Directors or their representatives.
  - c. Eligibility**

The two Program Directors or representatives shall be selected from Eligible Program Members.
  - d. Nominating Procedure**

A 15-day nominating period will commence following the Annual Meeting each year in which an election is held. Nominations will be accepted from Program Directors from Eligible Program Members. A minimum of two nominees will be required to hold election of Nominating Committee members and a maximum of four nominees will be included on the election ballot. Nominees included on the election ballot will be those who received the highest number of nominations. Following the nominating period, Program Directors or their representatives shall be notified of their nomination to be on the ballot for the Nominating Committee elections and given 15-days to accept or decline their nomination.
  - e. Selection Procedure**

The two Program Directors or their representatives will be selected by electronic votes cast by Program Directors from Eligible Program Members during a 15-day voting period. The two nominees receiving the highest tally of votes will be elected to the Nominating Committee.
  - f. Terms of Office**

No member of the Nominating Committee shall serve more than 3 consecutive years (exception – ICBD Director). The elected committee members shall serve from the date

of their election. The previous committee members serve until the end of the voting period for new committee members.

2. Other Standing Committees: These committees work closely with the Executive Committee.
  - a. Chairs of the Other Standing Committees shall be voted on by Members at the Annual Business Meeting. Term limits for the chair shall be limited to a maximum of three years. Members who are interested in chairing or serving on a Standing Committee may approach an Executive Committee member.
  - b. The Annual Scientific Meeting Committee shall be composed of the Executive Committee, the ICBDSR Coordinator, and the host of the current and following Annual Meeting.
  - c. The Awards Committee (e.g., Distinguished Service and Alessandra Lisi) shall be composed of the Executive Committee, the Director of the Centre and up to two other appointed members.
  - g. The Internal Audit Committee, for financial issues, shall be composed of three non-officer members proposed by the Executive Committee and elected at the Annual Business Meeting.

#### **C. Duties of the Committee Chairs**

On behalf of the committee members, the Committee Chair shall be responsible for the preparation of a written or verbal report, at least annually, to the Executive Committee.

#### **D. Ad Hoc Committees**

Other Ad Hoc Committees may be convened (e.g., Communications/Website, Scientific/Publications). Members will be suggested or appointed by the Executive Committee or Centre Director.

### **IX. BUDGET AND FINANCES**

#### **A. Financial Year**

The financial year of the Clearinghouse shall commence on January 1st and end on December 31.

#### **B. Sources of income**

The Expenses of the Clearinghouse shall be met by the dues of the Members and Affiliates, by grants from governmental bodies, private enterprises and foundations, by voluntary contributions, by incomes from registration in the Scientific Annual Meeting or other ICBDSR's educational activities, and by the sale of publications and services. Any excess receipts shall be applied to the furthering of the stated objectives and functions of the Clearinghouse.

#### **C. Dues**

1. Annual dues will be required for Members and may be required for Affiliates.
2. The amount of annual dues payable for the next financial year by each Member and Affiliate shall be proposed by the Executive Committee and ratified by a majority vote at the Annual Business Meeting.
3. Annual dues for Members and Affiliates for each financial year shall be payable by 30 June or any date set by the Executive Committee in the financial year to which they relate as described in the letter with instructions for payment distributed annually, entitled '*Procedures for payment of annual dues and exemption requests*'.
4. Dues shall be payable for the year following the admission to new membership and annually thereafter at such times as may be fixed by the Executive Committee.

#### **D. Exemption for payment of dues.**

1. Members with documented financial difficulties or other extenuating circumstances may apply to the Executive Committee for full or partial exemption. Exemption requests do not apply to Affiliates.

2. The Executive Committee will review the requests for exemption and decide on the requests before the Annual Business Meeting. If an Executive Committee member is requesting an exemption for payment of annual dues, another Member, not part of the Executive Committee will be co-opted to review and to decide on the request.
3. Approved exemptions will require compensatory contribution(s) from the Member as determined by the Executive Committee.
4. A full or partial exemption of annual dues may prevent the Member from receiving a travel stipend if requested to attend the Annual Meeting, at the discretion of the Executive Committee.

#### **E. Budget**

1. The Executive Committee shall prepare the proposed budget for the year to come, updated budget for the current year and financial report for the previous year, and mail them to all Members at least 60 days prior to the Annual Business Meeting.
2. The annual operating budget amount can be changed by the majority vote of the Members at the Annual Business Meeting.
3. The budget shall be adopted by a majority of the votes cast at the Business Meeting.

### **X. ANNUAL BUSINESS MEETINGS**

#### **A. Venue**

Members shall meet annually at the time and place usually determined at the previous Annual Business Meeting and if not so determined, as determined and notified to members by the Executive Committee.

#### **B. Notification**

Written notice of an Annual Business Meeting with the proposed agenda shall be mailed to each Member at least 60 days before the meeting.

#### **C. Invitations to Annual Business Meetings**

1. The Program Director of each Member may send one voting representative to the Annual Business Meeting. If the Member has voting right, its representative can exert such voting right.
2. The Program Director may invite additional members of his/her staff to attend the Annual Business Meeting as a non-voting representative.
3. The Executive Committee may invite Affiliates and other guests to the Annual Business Meeting whose presence is considered as beneficial to the Clearinghouse.

### **XI. QUORUM**

1. A quorum at the Annual Business Meeting shall consist of not less than 50% of the total number of the Members with voting rights (with reference to *Section V paragraph D*).
2. The quorum shall include members who are not in attendance but who have provided a written proxy (which may be provided by postal or electronic media) to a member of the Executive Committee or another voting Member who is present for the purpose of voting at the Annual Business Meeting.
3. In case the Program Director is not able to attend the Annual Business Meeting, he/she can also designate another person representing the Program at the Annual Business Meeting.
4. The proxy, including the name and date of the meeting and signed by the non-attending Member and the receiver of the proxy, must be received by the Secretary not less than 24 hours before the date of the meeting in order to be valid.



5. In case a quorum can not be reached at the Annual Business Meeting, including the proxies, voting will be done after the meeting by other means (postal or electronic). The Secretary will be in charge of organizing the post-meeting voting procedures.

## **XII. ORGANISATIONAL DISCIPLINE**

### **A. Loss of Voting Rights**

Voting rights of Members are lost at the Annual Business Meeting if, in that year, dues are not paid or an exemption was not applied for, subject to the provisions of *Section IX paragraph C (Dues)* and *paragraph D (Exemption for payment of dues)*.

### **B. Suspension of Membership**

1. A program which, after assessment by the Executive Committee, has not fulfilled the criteria laid down in *Section V paragraph A (Qualifications and Criteria)* and *paragraph C (Responsibilities)* for 2 years, or has not paid dues up to date for 2 years (without an exemption granted by the Executive Committee), subject to the provisions of *Section IX paragraph C (Dues)* and *paragraph D (Exemption for payment of dues)* may be suspended by a majority of votes cast at the Annual Meeting.
2. A suspended program may be invited to become Affiliate or may apply to become Affiliate. Acceptance is at the discretion of the Executive Committee.
3. Membership of a suspended Member may be re-installed after request of the suspended program if procedures and coverage have not changed in recent years. If the situation of a suspended Member has changed extensively in the opinion of the Executive Committee, a new official application is needed.
4. Apart from what is expressed in point 1 under this same paragraph B of Section XII, if a Member is not complying with the purposes, objectives and functions of the Clearinghouse, the Executive Committee may, by written notice to the Member, suspend that Member's membership.

### **C. Resignation**

A member can resign from membership by sending an official resignation letter to the Executive Vice Chair.

## **XIII. OFFICIAL LANGUAGE**

The official language of the Clearinghouse shall be English.

## **XIV. PROCEDURE FOR AMENDING BYLAWS**

Proposed amendment(s) of Bylaws should be sent 60 days before the Annual Business Meeting to the Executive Vice Chair and they will be sent 31 days before the Annual Business Meeting to all Program Directors. The proposed amendments shall be discussed and adopted upon the affirmative vote of at least two-thirds of the votes cast at the Annual Business Meeting as long as there is a quorum at the meeting.

## **XV. ADOPTION OF BYLAWS**

These Bylaws shall become effective when accepted by at least two thirds of the votes cast at the Annual Business Meeting of the International Clearinghouse for Birth Defects Surveillance and Research.