

## **Commission on Novel Technologies for Neurodevelopment CNVs**

**Mission:** Establish a patient-led Commission to rapidly tackle scientific and financial resources collectively to prioritize treatment for those living with neurodevelopmental chromosome disorders.

\*Definition of “Commission: -a group of people officially charged with a particular function.”

“Commission: -bring (something newly produced) into working condition.”

**Vision:** Advance the field of technological discovery for treatment of neurodevelopmental disorders with a focus on copy number variants

### **Background and Purpose:**

Founded by Project 8p Foundation, Dup15Q Alliance, and Ring14 USA, the Commission on Novel Technologies for Neurodevelopment CNVs is a consortium currently focused on studying copy number variations, including Chromosome 8p, Dup15q and Ring 14 and related CNV disorders. The short term and long term goals all support the mission for treatment:

#### **Short-term goals:**

1. Foster team science on proposals and accessing funding through collaboration and synergy, under the premise that collectively we can make more progress than what can be achieved individually.
2. Create a Neurogenetics Data Platform and Biorepository that is interoperable and has value for patients, families, clinicians, and researchers to participate and contribute to
3. Bridge gaps in knowledge and resources by summarizing latest developments and approaches, and identifying needs, through oral and written presentations (e.g., conferences, research roadmap, and review articles)

#### **Long-term goals:**

1. Accelerate research by identifying and developing novel methods, tools and technologies
2. Provide strategic direction and support in order to grow and increase the impact of the CNV scientific community
3. Enhance the active relationship between researchers and the patient/family community on a global basis
4. Serve as an umbrella for multiple chromosomal disorders and destination for large CNV research
5. Maximize political awareness and financial capital through targeted promotion of key stakeholders

Among other advantages, benefits of this cooperative approach are expected to include the strengthening and improving of ideas via discussion with fellow experts, the opportunity to attract additional resources in support of proposed projects, access to larger samples and data sets, better analytical tools, and sharing of complementary skills.

It follows that membership in the Commission on Novel Technologies for Neurodevelopment CNVs carries advantages for which some sacrifices of autonomy are considered to be a reasonable price – the collective benefits considerably outweighing the individual restrictions.

### **Ethos and Guiding Principles:**

1. Leadership with patients and their advocates as partners to collectively understand the nature of these diseases and remedies under the commonality of neurodevelopmental large chromosomal variations
2. Promote open and creative brainstorming to drive innovative approaches
3. Support a culture of trust and respect
4. Pro-Active participation and belief that a community approach gets us to the realization of helping patients
5. Commitment to freely sharing and transparency of data, biomaterials, and methods to optimize and expedite impact
6. Cooperative approach with openness about negative results and trials, experimental shortcomings, and failures
7. Adapting in a dynamic manner to reassess therapeutic goals and change direction when necessary
8. Overcome boundaries to unfold into borders that can be crossed with regular and effective communication
9. Be inclusive, equitable, and encourage diversity
10. Ensure representation of neurodevelopmental chromosomal disorders in funding, advocacy, drug development and other regulatory agencies

### **Organizational Structure and Membership:**

The *Collaborative* is the authoritative coordinating body for the efforts of the Commission on Novel Technologies for Neurodevelopment CNVs. All Principal Investigators within the Commission on Novel Technologies for Neurodevelopment CNVs are strongly encouraged to include their colleagues, including junior faculty MDs and PhDs, PhD students and postdoctoral fellows, within the Collaborative. The number of members should be fair and balanced, and the contribution of each partner should be evident to the *Collaborative* and indicated upon request. For additional members added after the initial conception of the Commission on Novel Technologies for Neurodevelopment CNVs, the Steering Committee will decide whether an applicant is admitted to the consortium and will communicate this decision in a transparent manner.

We recognize that not all collaborative projects may be of interest or hold the same value to all members. Collaborative projects are those that have been reviewed and discussed by all members but do not have to include all members.

The *Collaborative* acknowledges that even though a significant portion of the research will be performed by junior investigators (PhD students, postdoctoral fellows), the junior investigators in the field are naturally disadvantaged in large collaborative projects due to the limited number of leadership roles made available in team science, and the ongoing emphasis by most academic institutions and

funding-agencies on contributions represented by first authorship or senior authorship in manuscripts. The *Collaborative* will make a concerted effort to compensate for this imbalance by insuring that: (a) contributions of all junior investigators will be explicitly and fully stated in manuscripts; (b) senior investigators advocate strongly for junior investigators in the promotions and funding process by including detailed descriptions of the junior investigator's creative contributions and related attributes in letters of reference; (c) junior investigators have the opportunity to take lead roles and assume first-authorship for spin-off projects; (d) junior investigators have the opportunity to present results at high-profile symposia and related events; and (e) junior investigators are actively involved in the key decision making processes of the *Collaborative*. The *Collaborative* considers these junior scientists as future leaders in the field and feels responsible for their mentoring for leadership in the field.

### **The Collaborative consists of three parts:**

1. Steering Committee - will determine the overall strategic direction aiming for transparency, timely communication, effective coordination, and a sharing of responsibilities, challenges, and opportunities among cohort members. The Steering Committee will designate a 3-person Publication Committee, with one person serving as Chair, from its membership.
2. Working Groups - Temporary *ad hoc* groups established by the Steering Committee to pursue specific and time limited projects that are better handled by smaller, specialist groups. Working Groups will report progress and findings to the Steering Committee.
3. Regular Members- A large group with no strictly defined membership criteria, not only limited to principal investigators, but all individuals providing intellectual contribution to the Commission on Novel Technologies for Neurodevelopment CNVs activities.

### **Publishing/Authorship**

All project proposals must include a specific publishing/authorship plan.

Typically, the plan will be one of the following three options taken from various team science models:

- A *full* Commission on Novel Technologies for Neurodevelopment CNVs paper. These are papers that present data or other information based on essentially the full breadth of Commission activities, such as a comprehensive study involving genomic and phenotype data derived from numerous cohorts, or a paper presenting a conceptual overview of the work of the Commission. The Commission is listed as the author (along with other Collaboratives/Consortia, as appropriate), with a list of individual contributors made according to the journal's style preference most likely in alphabetical order in a contributor section. Byline authors may be acknowledged if they have contributed substantially to the conception or design of the work. No individual Member will be designated as a single corresponding author – the corresponding authors will be listed as the Collaborative with a mailing and email address.
- A *partial* Commission on Novel Technologies for Neurodevelopment CNVs Collaborative paper: Individual authors listed. These are papers based on work directly associated with a subset of the Commission's activities, such as studies of iPSCs derived from a specific cohort, or clinical

observational study. The Collaborative name is included in the author list, along with other Collaboratives/Consortia, as appropriate.

- A local paper: These are papers describing work done by investigators outside of the Commission, but relying on data provided by the Commission. These should simply acknowledge the Commission on Novel Technologies for Neurodevelopment CNVs Collaborative.

Draft manuscripts and abstracts with proposed Collaborative work will be circulated to all members for review by a certain deadline. Disputes will be determined by the Publication Committee. All publications by the Commission will be open access.

Junior scientists (PhD students, postdoctoral fellows) will be given preference in presenting data of the Collaborative at conferences.

Collaborative members will be reasonable and self-critical in their claims for authorship.

For any research that would rely wholly or in significant part on Collaborative data or resources, members are required to present and discuss their ideas within the Collaborative Steering Committee. This principle of “no surprises” extends to all new analyses, poster and oral presentations, manuscripts and other tools of the trade. The members acknowledge that "conflict of interest" can have a wide range of interpretations within the international framework of the Collaborative. Therefore, members are encouraged to proactively indicate conflicts if they feel that they might arise.

#### **I AGREE:**

1. To consider participation in projects proposed, primary and secondary analyses proposed by the Collaborative
2. To abide by the guidelines for the CNVs database (to be named officially) that will be set forth for data access, use, and contributions to the database. Participants and sites who have access to the database agree that they cannot use the entire dataset on their own, for purposes other than to perform joint analyses pre-approved by the committee. Each site will be able to access and download their own data for further analysis without permission from the broader group.
3. To abide by the guidelines for authorship and publication, and other guidelines described in this document.
4. To openly declare conflicts of interests that will arise during the participation of Commission on Novel Technologies for Neurodevelopment CNVs, such as the participation in related projects, awareness of information that significantly alters the interpretation of the Commission data, or commercial interests regarding to results of the Commission on Novel Technologies for Neurodevelopment CNVs data.

5. To try and solve conflicts relating to data arising from Commission on Novel Technologies for Neurodevelopment CNVs jointly and peacefully. Such a situation may arise if data from the Commission would add to pre-existing projects of two or more collaborators, resulting in conflicts regarding the use of the data. If a joint decision cannot be reached, the decision of the Steering committee is binding.
6. Not to distribute, copy, or communicate any data or privileged information to individuals who are not members without consent of the entire Collaborative. This includes any other existing collaborators who are not members of the Commission on Novel Technologies for Neurodevelopment CNVs. Privileged information includes results of any unpublished analyses completed by members of the Collaborative.
7. Not to distribute or copy any data collected by the Collaborative without prior written consent of all Steering Committee members.
8. That the Steering Committee will review and evaluate future scientific opportunities and will make recommendations regarding the needed expertise and research program to maximize those opportunities in the best possible way.
9. That failure to uphold this agreement may result in my expulsion from the Commission on Novel Technologies for Neurodevelopment CNVs Collaborative (but I will still be bound by publication guidelines on Commission on Novel Technologies for Neurodevelopment CNVs Collaborative work, as described above).

Signature

Date

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Please print name

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Affiliation

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