

Organization Overview:

The Dup15q Alliance is the patient advocacy group representing those diagnosed with Dup15q Syndrome. The Alliance empowers individuals living with dup15q syndrome and other related rare diseases to reach their full potential by advancing breakthrough research and life-changing therapeutic treatments, supporting families affected by dup15q, and promoting advocacy.

Chromosome 15q11.2-13.1 duplication syndrome (dup15q syndrome) is a clinically identifiable neurodevelopmental syndrome that occurs when there are extra copies of genes within the 11.2-13.1 region of chromosome 15, and results in a number of symptoms that may include, hypotonia, epilepsy, cognitive delay, motor delays, autism, and subtle facial features.

Position Summary:

The Dup15q Alliance seeks to contractually engage with a candidate to conduct a thorough summary of the current research being conducted into Dup15q Syndrome and assist with developing a forward looking research roadmap. This exercise will require contacting and interviewing academic researchers and clinical researchers from which a clearly defined list of both active research projects and research gaps will be cataloged.

After completing the survey portion of the project, the candidate will be expected to facilitate discussions with the academic researchers attending a closed-door scientific conference on August 1 and 2 at the Angelman Syndrome Foundation and Dup15q Alliance Scientific Conference. The feedback from these discussions is to be synthesized in a manner that identifies a consensus on the preferred research plan.

The ideal candidate will have an advanced degree with PhD preferred. Experience as an interim or contract-based CSO in the non-profit patient advocacy group space would be ideal but is not required.

Deliverables and Responsibilities:

The chosen candidate will be expected to provide the Dup15q Alliance with

- A comprehensive written digest of the current research landscape. This includes current research targets, researchers, projects and funding sources.
- Weekly updates on progress of the project via regularly scheduled meetings
- A scientific consensus derived from researcher interviews identifying short, medium and long term targets for translational research towards creation of a research roadmap for the Dup15q Alliance.
- Required in-person participation in August 1-2 meeting

Length of contract:

Contractual arrangement is an anticipated 3 month engagement; dates to be determined based on commencement of the project.