



FON Project Collaboration Policy

PURPOSE

The Fontan Outcomes Network (FON) has a strong interest in facilitating and empowering work that advances knowledge about single ventricle heart disease and the Fontan circulation. While FON itself will include many different projects, including quality improvement (QI) and research, there will be aligned work that may not originate or be coordinated or fully managed by FON. FON hopes to use its network to enhance the impact of rigorous Fontan-related projects throughout our community.

This document outlines a framework for FON to consider communication, support and collaboration with other initiatives related to single ventricle/Fontan circulation and patients, such as ad hoc research projects and larger, programmatic initiatives. Because of the diversity of potential projects, there will be nuances and considerations specific to each project; it is anticipated this guideline will evolve over time, and FON will remain flexible when considering new proposals.

POLICY

FON encourages communication and collaboration among QI, research or educational initiatives that target a similar population.

Such initiatives that do not originate FON, may apply to FON for consideration of information sharing, cross-promotion, or direct collaboration. FON wishes to be a community resource for dissemination and posting of important Fontan related initiatives. For research, the IRB (Institutional Review Board) protocol, informed consent form and IRB approval letter will be required for review prior to posting (if applicable – or other regulatory documentation as needed for QI or educational proposals). A brief [<100 word] statement summarizing the initiative will be required along with specific information on the study relevant to participation.

Proposals will be reviewed by the relevant FON workgroup (e.g., Research) and directed to FON's Executive Leadership Team if direct collaboration is requested. A FON representative will reach out to the applicant via email if clarifications are needed.

Decisions around the level of collaboration and engagement for FON with other QI/research/educational initiatives will be based upon the following FON principles, as well as relevant legal or regulatory considerations. Does the project:

- Advance knowledge of single ventricle heart disease and the Fontan circulation, with the goal of transforming outcomes?
- Promote rigorous, reproducible work?
- Represent a full spectrum of perspectives and contexts?
- Improve the capacity and cohesiveness of the single ventricle heart disease community?
- Maintain the integrity of the Fontan Outcomes Network and otherwise act to enhance the network's long-term value for individuals with single ventricle heart disease?

EXCLUSIONS

In general, FON will not provide endorsement or support (e.g., letters of support, endorsements for grant applications) for non-FON based QI or research projects. Such requests will be reviewed by the FON ELT (Executive Leadership Team), and there may be rare exceptions where such support is extended. This is in contradistinction to projects originating from or otherwise embedded within FON which are eligible for such endorsement and support.

IMPLEMENTATION

FON will accept submissions on a rolling basis for collaborative QI/Research proposals. The application is available on FON's website: www.fontanoutcomesnetwork.org/. FON will review the application and provide a timely decision regarding collaboration.

OVERSIGHT

All revisions of this policy must be approved by the FON Executive Leadership Team. This policy will be reviewed every three years or sooner if deemed necessary.