Case Study

Advancing Research in Single Ventricle Heart Disease: The SOURCE Study

Who is Additional Ventures

Additional Ventures is a nonprofit organization dedicated to advancing research and improving outcomes for individuals with single ventricle heart disease — a set of complex, lifelong congenital heart defects. Founded in 2020, the group brings together researchers across diverse fields to accelerate progress in this under-resourced field. To date, Additional Ventures has committed over $11.5 million to advance new treatments and cures for single ventricle heart disease, for which there is currently only palliative treatments available.

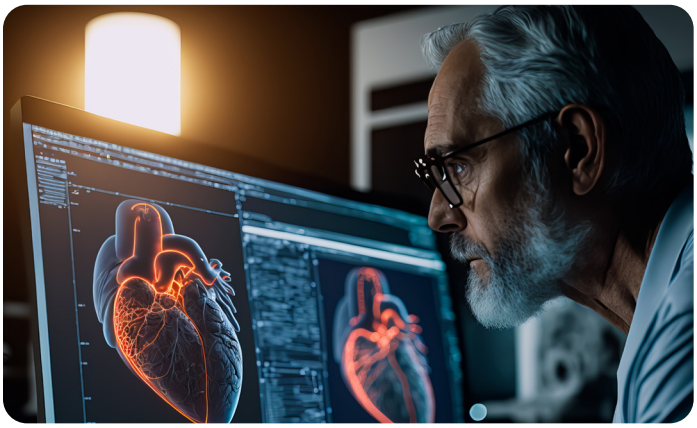
Why SOURCE and their goals

Recognizing the lack of comprehensive genetic and clinical data as a barrier to discovery, Additional Ventures launched Single Ventricle SOURCE, a large scale genomics sequencing study.

The goal is to assemble the world's largest genetic and clinical dataset of single ventricle patients and their immediate biological family members by enrolling at least 5,000 patients and 5,000 family members and combining genetic sequencing with clinical records.

The de identified dataset (reSOURCE) will be made accessible to all researchers, free of charge, through a streamlined process.

An API connects the SOURCE platform to the genetic sequencing lab and the platform where reSOURCE will be accessible to researchers, sending only de identified data to protect participant privacy.



Impact already happening

Even as enrollment continues, SOURCE is already giving back. Participants are receiving actionable secondary genetic results through genetic counselors, and SOURCE is providing quarterly study updates to all enrolled participants.

This early return of information provides value to patients and families and honors their generous contribution to the SOURCE study.

Celebrating progress: SOURCE registry milestones

Since its launch in December 2024, SOURCE has enrolled nearly 1,000 participants across 44 states.

Recruitment includes both direct to participant enrollment and in clinic participation, beginning with Boston Children's Hospital and currently expanding to nine additional clinical sites.

SOURCE is also partnering with institutions that house biorepositories to integrate data from these other datasets.

Looking ahead

The public launch of the de-identified reSOURCE dataset planned for October 2026, with updated data releases anticipated at least annually. By making data broadly accessible to all researchers, SOURCE is catalyzing research quickly and paving the way for better treatments, and, ultimately, cures.

Why IQVIA

Additional Ventures partnered with IQVIA to design and build the participant-facing experience and technical infrastructure for SOURCE, enabling both direct-to-participant and in-clinic enrollment. The platform has been designed to reduce study participant burden and ensure data completeness and standardization.

"IQVIA was chosen as our partner to build the SOURCE study platform because they demonstrated to us proven success in designing and operating other registries and the ability to meet the complexities of our study. They have brought a wealth of knowledge and experience to building the platform that is the scaffolding of the SOURCE study"

— Diane Pickles, Director of SOURCE

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