SCHD
Structural & Congenital Heart Disease

Tech Science Press

http://doi.org/10.32604/schd.2026.085038

REVIEW

Improving Fetal Cardiovascular Care through the Fetal Cardiac Intervention Registry and the Fetal Heart Society

Whitnee Hogan[1,2,*], Thomas S. Przybycien[3,4] and Anita J. Moon-Grady[3,4]

[1]Division of Pediatric Cardiology, Department of Pediatrics, University of Utah, Salt Lake City, UT, USA
[2]Primary Children's Hospital, Salt Lake City, UT, USA
[3]Division of Pediatric Cardiology, Department of Pediatrics, University of California, San Francisco, San Francisco, CA, USA
[4]UCSF Benioff Children's Hospital, San Francisco, CA, USA
*Corresponding Author: Whitnee Hogan. Email: whitnee.hogan@hsc.utah.edu

Received: 04 May 2026; Accepted: 23 July 2026; Published: 31 July 2026

ABSTRACT: Improvements in fetal cardiac imaging have highlighted the need for large, multidisciplinary collaborations to further advance fetal cardiovascular care. The Fetal Cardiac Intervention Registry (IFCIR), established in 2011, aims to improve outcomes in fetuses with congenital heart disease (CHD) considered amenable to fetal cardiac intervention (FCI). The registry compiles data from multiple international centers to better define indications, selection criteria, procedural techniques, complications, and outcomes of FCI. The Fetal Heart Society (FHS), founded in 2014, is a non-profit organization dedicated to advancing the understanding of *in utero* cardiovascular physiology through collaborative research, education and mentorship. The IFCIR includes more than 850 maternal-fetal dyads, including 458 fetal interventions from 29 international centers, and has provided important insights into procedural outcomes and the need for refined patient selection criteria to optimize fetal and neonatal outcomes. The FHS has grown to over 1100 members across 37 countries and has expanded its efforts in research, education, and mentorship. More than 20 multicenter research projects have been initiated, alongside the development of multiple educational resources, including lesion-specific materials and multidisciplinary webinars, as well as growing mentorship opportunities. The IFCIR and FHS have substantially advanced the field of fetal cardiovascular care through international collaboration. This narrative review summarizes their development, key contributions, and future opportunities to improve outcomes in fetal CHD.

KEYWORDS: Fetal cardiology; congenital heart disease; prenatal diagnosis; fetal cardiac intervention

1 Introduction

Advances in fetal cardiac imaging and multidisciplinary perinatal care have transformed the management of fetuses with congenital heart disease (CHD) over the last several decades. What began as an initiative to diagnose severe CHD prior to birth has expanded to include earlier detection, longitudinal monitoring of disease progression, risk-stratification, potential fetal intervention, delivery planning, and family education and counseling. As the field evolved, the need for multicenter, multidisciplinary collaborations became apparent. Although several national and international congenital heart disease registries have formed and substantially advanced our knowledge regarding postnatal outcomes, they generally do not capture the detailed perinatal imaging, fetal physiology, maternal factors, and longitudinal prenatal data necessary to address many of the unique questions encountered in fetal cardiovascular care.

Recognizing this need, two international collaborations were established. The International Fetal Cardiac Intervention Registry (IFCIR) was created to systematically collect multicenter data on fetuses considered for a fetal cardiac intervention (FCI), providing a framework to evaluate patient selection, procedural techniques, complications, and clinical outcomes in specific cardiac diagnoses. The Fetal Heart Society (FHS) was later established as a multidisciplinary professional organization dedicated not only to advancing fetal cardiovascular research, but to also provide a platform for education, mentorship, and collaborative clinical practice across the spectrum of fetal heart disease. This narrative review summarizes the development, structure, and major contributions of the IFCIR and FHS, while highlighting current challenges and future opportunities to improve fetal cardiovascular care.

2 International Fetal Cardiac Intervention Registry (IFCIR)

2.1 History and Development

IFCIR was created in 2011 with the goal of improving the care and outcomes for pregnancies complicated by fetal CHD, with a particular focus on CHD lesions considered amenable to a FCI [1]. FCI has emerged as a potential therapeutic option for specific types of severe CHD lesions prior to birth, with the goal of preventing progression of disease, promoting growth of cardiac structures, improving stability at delivery, and improving long-term outcomes, including mortality [1,2]. The most common FCI performed is aortic valvuloplasty for cases of severe aortic stenosis (AS) with a high likelihood of progressing to hypoplastic left heart syndrome (HLHS) without intervention [1–5]. In these cases, fetal aortic valvuloplasty is performed with the goal of relieving left ventricular outflow tract obstruction, allowing improved blood flow through the left heart, promoting growth of left-sided cardiac structures, and therefore increasing the likelihood of a biventricular circulation after birth. Successful FCI was first reported in 1991 by Maxwell et al., with technically successful aortic valvuloplasties performed in 2 fetuses with severe AS [6]. In 2004, Tworetzky et al. reported a series of technically successful fetal aortic valvuloplasties in 14 fetuses and demonstrated improved growth in left-sided cardiac structures in technically successful cases [7]. These early experiences led to FCI in other cardiac diagnoses, such as severe pulmonary stenosis (PS)/pulmonary atresia with intact ventricular septum (PAIVS) [1,8–10] and HLHS with a restrictive or intact atrial septum (RAS/IAS) [1,2,11].

FCI is one of the more debated and evolving topics within fetal cardiovascular care. While proponents suggest that intervention may modify the natural history of disease and improve postnatal physiology, data supporting these interventions were initially limited to small case series from a select number of centers with limited long-term follow-up. Furthermore, FCI is associated with procedural risks to both the fetus and the pregnant patient, highlighting the need to identify the patients most likely to benefit from the procedure. Due to these concerns, there was a need for a registry to compile data from multiple institutions to better understand the indications, selection criteria, procedural techniques, complications, and fetal and neonatal outcomes.

In 2011, the IFCIR was created with 25 international centers. The registry is voluntary and includes both retrospective and prospective cases of potential FCI. De-identified data collected includes pregnancy, perinatal, operative, and perioperative details for maternal/fetal dyads who specialists at the local center believe could benefit from a fetal cardiac intervention [1]. In 2015, an initial report was published by the IFCIR that included 370 cases entered from 18 institutions that occurred between January 2001 and June 2014. There were a total of 245 that underwent FCI: 186 aortic valvuloplasty cases, 16 pulmonary valvuloplasty cases, 37 atrial septal cases, and 6 additional unclassified cases in the registry. Details regarding the success of FCI by year and procedure, demographics, complications, and pregnancy outcome were reviewed. This first large multi-center experience detailing FCI led to future lesion-specific reports from the IFCIR [1].

2.2 Target Population and Scope (Research)

The registry consists of maternal-fetal dyads with fetal CHD lesions considered amenable to FCI, such as severe AS, severe PS/PAIVS, HLHS with a RAS or IAS. De-identified data are entered into the Research Electronic Data Capture (REDCap) platform by the local site. There are over 250 variables, including demographic information, cardiac anatomic diagnosis and characteristics, ultrasound and echocardiographic findings, extra-cardiac or genetic anomalies, pre-operative factors, maternal/fetal intraoperative details, complications incurred at the time of the procedure or during the remaining pregnancy, technical success, pregnancy and neonatal outcome, including neonatal procedures and death [1]. Importantly, the registry includes technically successful and unsuccessful cases as well as cases that did not undergo FCI for reasons such as maternal contraindications, maternal preference, FCI not offered at the local site, or another non-fetal cardiac contraindication. This allows for comparisons in outcomes between successful and unsuccessful intervention cases as well as non-intervention cases.

2.3 Governance and Strategic Partners

The IFCIR was founded and led by Anita Moon-Grady, MD, at the University of California, San Francisco (UCSF), and Dick Oepkes, MD, PHD at Leiden University Medical Center in the Netherlands, and represents an independent group of medical centers and healthcare professionals. UCSF serves as the data coordinating center (DCC) for the IFCIR. A Steering Committee of active members from the participating centers reviews proposals involving the release of data to individuals for research purposes. Due to international privacy laws, data distribution is limited to participating sites and is not publicly available.

2.4 Present State

A total of 29 centers from 16 countries currently participate in the registry (Fig. 1). There are a total of 458 cases (302 AS, 75 PS/PAIVS, 77 RAS/IAS, 4 unlisted) entered at the time of publication (Figs. 2 and 3). To date, three major publications have reported outcomes from the IFCIR, each contributing lesion-specific insights into feasibility, safety, and clinical impact [1,11,12].

Figure 1: IFCIR sites at time of publication. See www.ifcir.org for current sites.

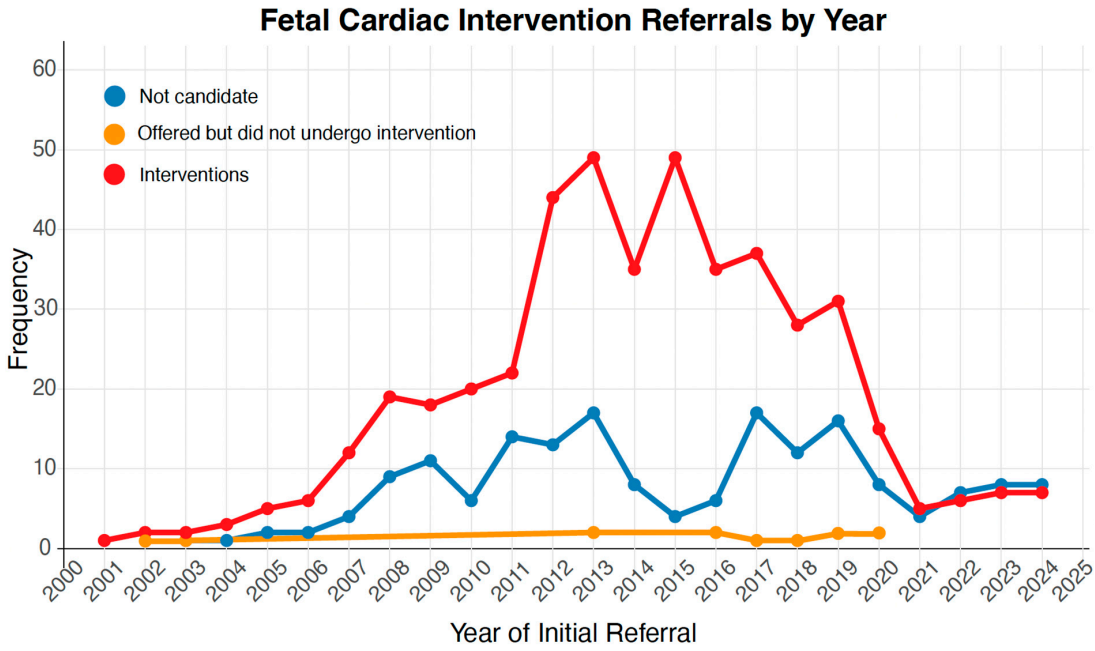

Figure 2: Fetal Cardiac Interventions in IFCIR by Year. There were a total of 458 fetal cardiac interventions entered through 2025. 100 aortic valvuloplasties were excluded from the figure as they were published in a prior report [4], and no subsequent entries were provided by this participant. The figure also excluded roughly 200 cases from a single large European center that were not available in the IFCIR at the time of manuscript preparation.

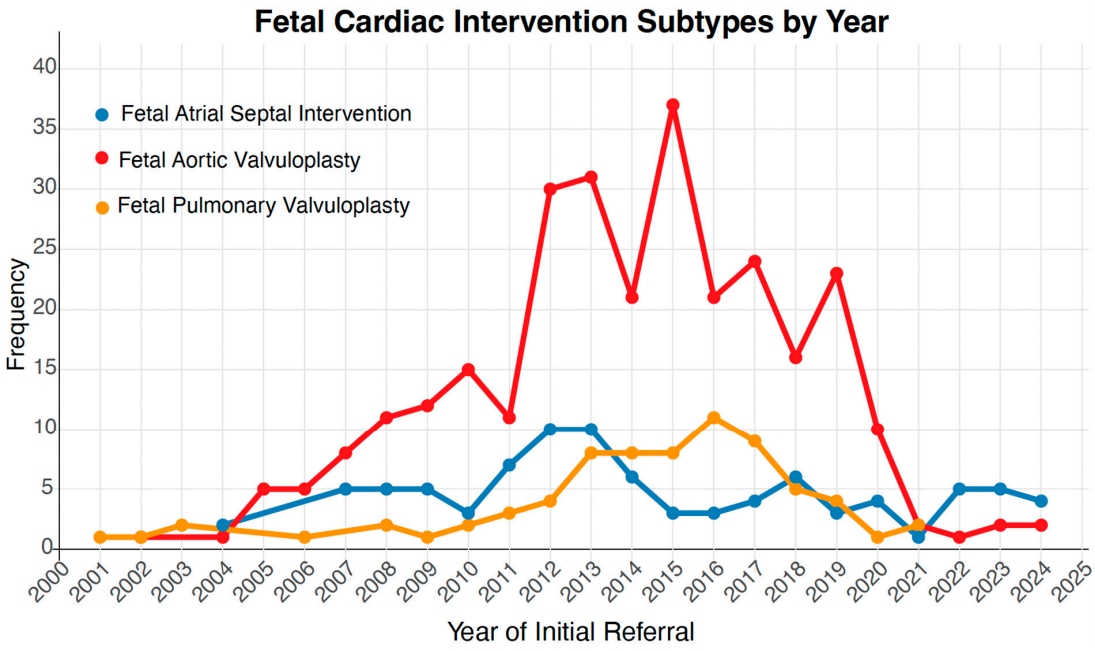

Figure 3: Fetal Cardiac Interventions in IFCIR by Intervention. There were a total of 458 fetal cardiac interventions entered through 2025. 100 aortic valvuloplasties were excluded from the figure as they were published in a prior report [4], and no subsequent entries were provided by this participant. The figure also excluded roughly 200 cases from a single large European center that were not available in the IFCIR at the time of manuscript preparation.

2.5 Examples of Where Outcomes Improved Due to Registry Data Insights and/or Intervention

Data from the IFCIR have provided critical insights into the feasibility, risks, and potential benefits of FCI, while also highlighting the need for standardized selection criteria.

HLHS with a highly RAS or IAS is a high-risk subset of patients with high rates of morbidity and mortality [13,14]. FCI with atrial decompression (balloon dilation vs. stent implantation) has been proposed as a potential intervention to improve stability at the time of delivery, as well as to improve the associated lung disease or lymphangiectasia that can develop from left atrial hypertension in the fetus. In 2017, the first multicenter experience of FCI in HLHS with IAS was published by the IFCIR. The report included 89 maternal/fetal dyads from 13 institutions from 2001–2015, with 47 dyads from 8 sites undergoing FCI (atrial septoplasty alone or with atrial stent placement). The procedure was successful in 77% of cases, with no maternal complications, but fetal complications were common, with a fetal demise rate of 13%. Successful intervention was associated with lower rates of cesarean delivery, need for immediate postnatal intervention, atrial restriction at birth, and neonatal resuscitation. The overall survival at discharge was low (35%) without a significant difference between groups [11].

Similar to the rationale for fetal aortic valvuloplasty, fetal pulmonary valvuloplasty has been proposed to improve outcomes in fetuses with severe PS or PAIVS by relieving right ventricular outflow tract obstruction (RVOTO), increasing flow through the right heart, and improving growth of the right heart structures [9,10,12,13]. In 2020, the first international multicenter experience examining the impact of FCI on PAIVS was published. It included 84 maternal/fetal dyads, of which 58 underwent pulmonary valvuloplasty at a median gestational age of 26 weeks. There were no maternal complications but a high rate of fetal complications, occurring in 55% of cases, including 7 deaths and 3 delayed fetal losses. Among those who underwent successful FCI, the tricuspid valve z-score improved throughout gestation. Among 60 liveborn with known outcome, there was a higher percentage having a biventricular circulation following a successful FCI (87 vs. 43%). These findings suggest a possible benefit to FCI for PS/PAIVS but highlight the high rate of fetal complications as well as the variability in FCI indications, leading to a call for uniform FCI selection criteria [12]. Collectively, these studies demonstrate the unique value of multicenter collaboration in generating evidence for rare fetal cardiac conditions that cannot be adequately studied through single-center experience alone.

2.6 Future State: Opportunities, Challenges, and Data Gaps

Given the rarity and complexity of FCI, continued progress in the field requires a collaborative, comprehensive, and transparent approach.

Key priorities include:

1. Development of standardized selection criteria
2. Optimization of procedural timing and techniques
3. Expansion of longitudinal outcome data
4. Potential regionalization to maximize training and expertise for better outcomes

Although the IFCIR has advanced our understanding of procedural feasibility, patient selection, and short-term outcomes, several important challenges and knowledge gaps remain. As a voluntary registry, participation is primarily limited to specialized centers that perform fetal cardiac interventions, introducing potential referral and selection bias as well as limiting the generalizability of outcomes. In addition, variations in patient selection criteria, procedural techniques, and peri-procedural management highlight the need for greater standardization across centers. One major challenge of the IFCIR is the limited long-

term follow-up data. While it provides insight into early procedural and neonatal outcomes, the impact of FCI on long-term outcomes such as later mortality, neurodevelopment, and quality of life remains unknown.

Expanding participation in the IFCIR is needed to ensure more comprehensive case capture across a variety of centers. Continued enrollment of fetuses considered for fetal cardiac intervention, including those who ultimately do not undergo intervention because of maternal or fetal contraindications, institutional practices, or family preference, is essential to better understand the natural history of these lesions and to facilitate meaningful comparisons between intervention and non-intervention cohorts. Coupled with more complete longitudinal follow-up, this comprehensive approach will provide greater insight into which patients derive the greatest benefit from FCI, refine patient selection criteria, and better define the long-term impact of these procedures on mortality, morbidity, neurodevelopment, and quality of life.

2.7 How to Get Involved

Participation in the IFCIR registry is free, voluntary, and open to institutions that perform FCI as well as those that do not currently provide FCI, due to the need for control/non-intervention cases. Participation requires local Institutional Review Board (IRB) and ethics board approval or waiver for submission of de-identified data and a bilateral data use agreement with UCSF as the Data Center. Additional information can be found at www.ifcir.org.

3 Fetal Heart Society (FHS)

3.1 History and Development

The formation of an international society focused on fetal and perinatal cardiac disease was first suggested in 2008 [15] and again in an editorial in 2014 [16]; the Fetal Heart Society (FHS) was established as a 501(c)(3) non-profit organization in October 2014 with the overarching goal of advancing the field of fetal cardiovascular care.

The mission of the FHS, as outlined in its bylaws, is [16–18]:

1. To advance the cause of research and education relating to the field of fetal cardiology and other reasonably related medical or scientific pursuits
2. To promote and encourage the development and advancement of the field of fetal cardiovascular diagnosis, management, and therapy
3. To promote the establishment of mutually beneficial relationships among the FHS members to enable the sharing of ideas and research collaboration
4. To foster and facilitate multicenter research and collaboration
5. To advance the field of fetal cardiovascular science and clinical practice by the establishment of the Fetal Cardiovascular Research Collaborative within the society

3.2 Target Population and Scope (Research, Education, Mentorship)

The FHS aims to improve the understanding of *in-utero* cardiovascular physiology by fostering organized research collaboration, education and mentorship [16–18].

3.2.1 Research

Fetal cardiovascular research has been a central focus of the FHS, primarily through the development of the Research Collaborative Committee (RCC). The RCC oversees the development, review, and execution of multicenter studies. To date, more than 20 prospective and retrospective research projects have been

initiated, spanning a wide range of topics. These include investigations into prenatal predictors of postnatal outcomes in specific CHD lesions, the impact of social determinants of health and other factors on prenatal detection and outcomes, and the exploration of novel imaging technology, such as utilizing fluid dynamics in the diagnosis of coarctation and the use of artificial intelligence (AI) to aid in improving prenatal detection of CHD [19]. Research proposals are submitted by active FHS members (who serve as principal investigators) and undergo a structured review process. Following approval of a project, a call to participate is sent to both active and affiliate members of the FHS. To streamline the regulatory aspects of multicenter research as well as data management, the FHS utilizes a data coordinating center (DCC). Each study includes a standard set of variables identified by the FHS, with additional variables added as needed according to the research project goals. De-identified clinical data are entered into a central database by the local site. De-identified imaging studies, such as fetal echocardiograms, neonatal echocardiograms, and cross-sectional imaging studies, including fetal magnetic resonance imaging (MRI) and neonatal MRIs, are uploaded to an image storage system within the DCC. Following completion and publication of a study, the dataset is available for use in ancillary studies, with a similar application and approval process. To better understand practice variation within fetal cardiovascular care, a separate process has been developed to aid in survey distribution throughout the FHS membership.

Ongoing research efforts are supported through regular RCC meetings, which provide a forum for progress updates, troubleshooting, and collaboration. In addition, the FHS holds an in-person Annual Scientific Session that highlights research from the FHS as well as other advances in fetal cardiovascular care.

3.2.2 Education

Given the multidisciplinary nature of fetal cardiac care, educational efforts must span multiple disciplines and provider types, in addition to patients and families. The FHS has prioritized education as an initiative for the organization and has developed several resources for subspecialty providers, sonographers, trainees, and patients. Resources include educational lectures on the performance of fetal cardiac screening, free multidisciplinary educational webinars, provider counseling sheets detailing specifics for common lesions to aid in counseling, and a patient/parent educational booklet.

3.2.3 Mentorship

To continue to advance the field of fetal cardiology, mentorship has become an important focus within the FHS. Mentorship opportunities are embedded within research collaborations, educational initiatives, and organizational leadership. Due to the need for more formalized mentoring, a mentoring program has been developed that pairs early-career providers with experienced clinicians and investigators who serve not only as a clinical resource but also provide career mentorship.

3.3 Governance and Strategic Partners

The FHS is governed by a Board of Directors composed of the President, Vice President, Secretary, Treasurer, Research Officer, Publications Officer, Education Officer, Immediate Past President, Program Leaders Committee Officer, and three Directors at-large [20]. Board members are elected by votes cast by the active members of the FHS and serve 3-year terms. The FHS is further supported by several committees, led by Committee Chairs, including the Research Collaborative Committee, Publication Committee, Education Committee, Membership Committee, Website Committee, DCC Task Force, Finance Committee, Correspondence Committee, Conference Committee, Program Leaders Committee, Global Affairs Committee,

Nursing Committee, Fundraising Task Force, Social Media Committee, Sonographer Committee and the Steering Committee [21].

The FHS is supported by Institutional and Industry Sponsors and maintains active engagement with its membership through twice-yearly meetings of its membership (one in person, one virtual).

3.4 Present State

The FHS consists of over 1100 members from 37 countries (Figs. 4 and 5). Membership spans a broad range of sub-specialties and provider types, including pediatric/fetal cardiologists, maternal-fetal medicine specialists, obstetricians, radiologists, neonatologists, geneticists, sonographers, nurses, and trainees. There have been more than 20 abstracts presented at national and international meetings, 7 publications using data from the FHS, and an additional 9 publications endorsed by the FHS. Educational offerings have expanded to include numerous free online webinars (these are also recorded and available to members at no additional cost), 5 annual Scientific Sessions, and widely utilized clinical resources. To improve collaboration between the FHS and other registries and organizations, the FHS has recently joined Cardiac Networks United.

3.5 Examples of Where Outcomes Improved Due to Registry Data Insights and/or Intervention

Research conducted through the FHS has generated important insights into both clinical outcomes and healthcare disparities in fetal cardiovascular care. In 2021, the first research paper published by the FHS evaluated the impact of socioeconomic status, race and ethnicity, and geography on the prenatal detection of HLHS and Transposition of the Great Arteries (TGA). The study included data on 1862 subjects from 21 centers and demonstrated that lower socioeconomic status, Hispanic ethnicity, and rural residence were associated with decreased prenatal detection of TGA, with lower socioeconomic status also being associated with decreased prenatal detection in HLHS [22]. These findings provide insight into the need for targeted interventions to improve access to high-quality prenatal care.

Subsequent multicenter investigations have focused on refining prenatal risk stratification within specific CHD lesions to aid in pregnancy management and counseling. For example, a 2023 study of congenitally corrected transposition of the great arteries (ccTGA) identified key prenatal risk factors associated with adverse outcomes, including the degree of tricuspid regurgitation, presence of arrhythmias, outflow tract obstruction, and worsening hemodynamics over gestation [23]. These findings have direct implications for prenatal counseling, surveillance strategies, and delivery planning for a rare and heterogeneous cardiac diagnosis.

The research within the FHS has also expanded beyond structural CHD lesions to evaluate the impact of extracardiac findings on the fetal cardiovascular system. Most recently, the FHS published the largest multicenter study identifying echocardiographic metrics associated with fetal demise in cases of advanced-stage twin-twin transfusion syndrome (TTTS). The study included 285 twin gestations and identified both donor and recipient echocardiographic findings associated with fetal demise, such as abnormal umbilical cord Dopplers, abnormal cardiac output, higher LV myocardial performance index, and others [24]. These data provide valuable tools for risk stratification and clinical decision-making.

In addition to original research publications utilizing FHS data, there have been expert consensus statements from the FHS regarding advances in the field, such as the performance of Early Fetal Echocardiography [25] and the use of Maternal Hyperoxygenation [26] during fetal echocardiography.

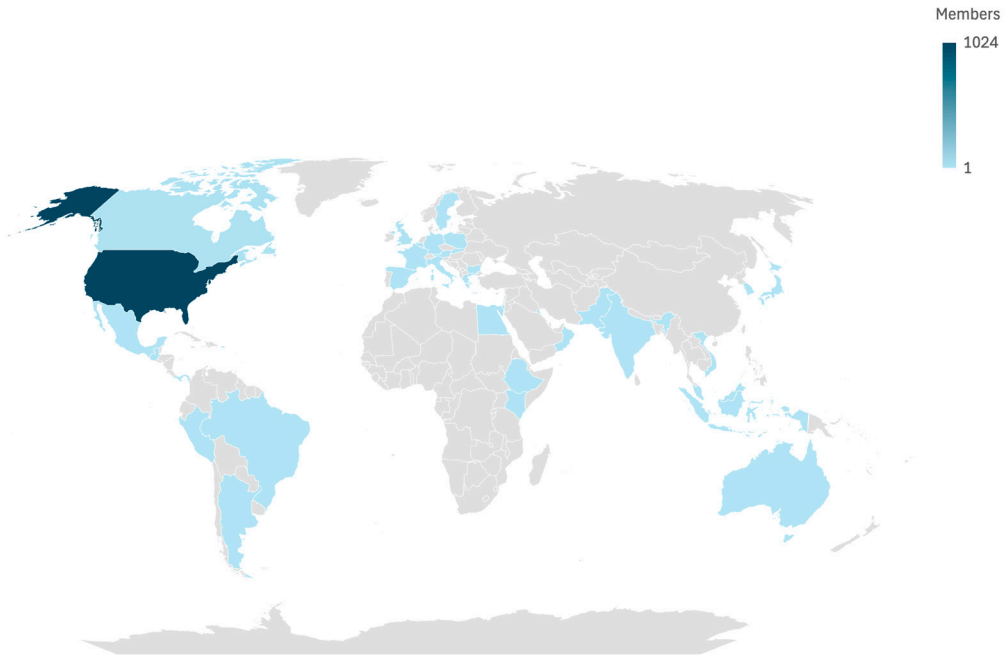

Figure 4: FHS member representation by country at the time of publication. See www.fetalheartsociety.org for current representation.

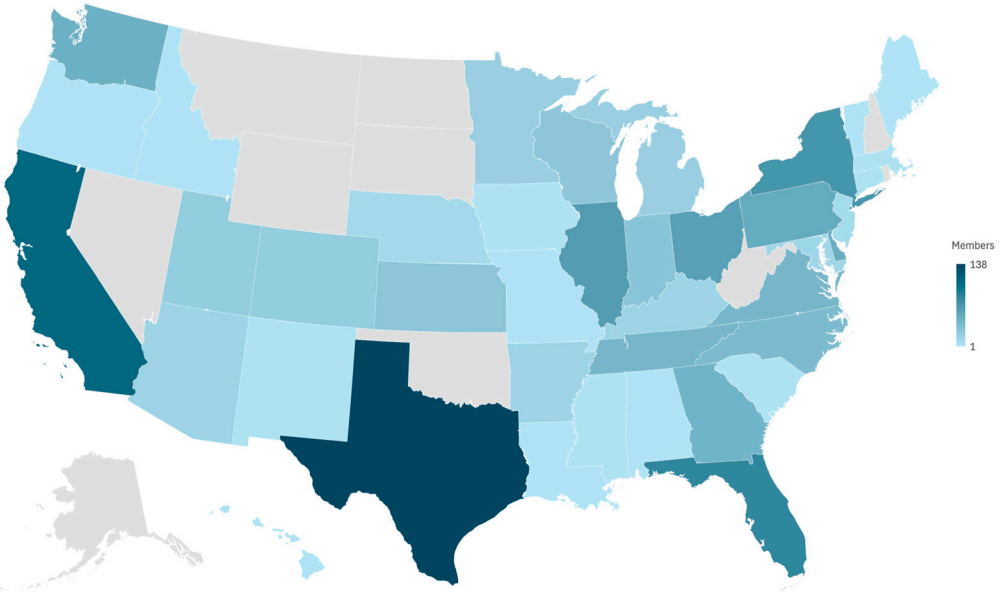

Figure 5: FHS member representation by state at time of publication. See www.fetalheartsociety.org for current representation.

3.6 Future State: Opportunities, Challenges, and Data Gaps

The FHS has identified several opportunities in the advancement of fetal cardiac care [17]:

1. Improving diagnosis and detection of CHD

2. Improving the understanding of fetal cardiovascular hemodynamics, progression of disease, and factors that predict outcomes
3. Standardizing protocols for fetal cardiac imaging and management across disciplines
4. Advancing fetal therapy

Prenatal detection rates for CHD remain suboptimal in many regions [27–30], limiting the impact of other advances within the field. Improving detection of fetal CHD requires investigation into barriers, education to front-line providers, and implementation of targeted interventions, such as hands-on training with a fetal cardiac simulator to increase exposure to fetal CHD or incorporation of artificial intelligence in ultrasound screening. Despite advances in the understanding of fetal cardiac physiology, there remain significant limitations to predicting outcomes for individual patients, likely related to the significant heterogeneity both between and within specific CHD lesions. Continued multidisciplinary and multicenter collaboration into the intricacies of specific CHD lesions and the hemodynamic changes that occur over time will be essential to refine risk models and better understand disease trajectories. Since fetal cardiovascular care spans diverse disciplines, there are variations in imaging and management protocols across specialties and locations [31–35]. There is room for improvement in the standardization of imaging, monitoring, and treatment that can be led by the FHS. Lastly, there have been efforts in fetal therapy, both in interventions such as aortic valvuloplasty for aortic stenosis and medical management such as the use of non-steroidal anti-inflammatories for severe Ebstein's anomaly [36,37] and the use of sirolimus in rhabdomyomas [38–40] that can only be properly evaluated through multidisciplinary collaboration and transparency.

Similar to other large international research networks and societies, continued growth requires broad participation from diverse institutions and patient populations to improve the generalizability of the research findings. Expanding engagement with centers in low- and middle-income countries and other resource-limited settings is a priority of the FHS and represents an opportunity to improve global representation. Participation in multicenter collaborations requires significant institutional commitment, including financial resources and regulatory oversight, creating barriers for some centers. Future efforts should focus on reducing these burdens through greater collaboration among registries and research networks with standardized data elements and shared infrastructure that facilitates more efficient data collection and sharing. The recent incorporation of the FHS into Cardiac Networks United provides an opportunity to harmonize data collection across complementary registries, reduce duplication of effort, and facilitate more comprehensive longitudinal investigation of patients with congenital heart disease.

3.7 How to Get Involved

The FHS offers individual membership and membership via institutional or industry sponsorship. There are active and affiliate member options. Affiliate members have access to all FHS web content and the ability to participate in FHS studies. Active members can additionally propose new projects as the PI, vote in FHS elections, and serve in FHS leadership positions. Institutional sponsorship allows for participation by multiple providers at the institution, the number dependent on sponsorship level, as well as recognition on FHS communications and the FHS Website. Additional information can be found at www.fetalheartsociety.org.

4 Limitations

As a narrative review, this manuscript does not follow a systematic search protocol or formal evidence grading, and the selection of topics reflects the authors' perspective rather than an exhaustive synthesis. The IFCIR is a voluntary registry, and participation is largely limited to specialized centers, introducing

potential selection bias and limiting generalizability. Variability in patient selection, procedural techniques, and peri-procedural management across participating sites further complicates the interpretation of pooled outcomes. Both the IFCIR and FHS rely on self-reported data, which may be subject to reporting or entry errors, and long-term follow-up beyond the perinatal period remains incomplete. Membership and participation are not globally representative, with underrepresentation from low- and middle-income countries. Finally, the senior author's leadership roles in both organizations, while disclosed, represent a potential for unintentional bias in the interpretation of their impact. Despite these limitations, the review provides a balanced and timely summary of two important collaborations that have meaningfully advanced fetal cardiovascular care.

5 Conclusions

Over the last several decades, fetal cardiovascular care has evolved from isolated institutional experience to an internationally collaborative field of clinical care and investigation. The IFCIR and FHS have each played important roles in this evolution by advancing research, promoting education, and fostering multidisciplinary collaboration. Continued efforts to standardize clinical practice, expand longitudinal research, and strengthen global partnerships will be critical to improving the understanding and management of fetal cardiovascular disease and optimizing outcomes for fetuses and families affected by CHD.

Acknowledgement: The work of the International Fetal Cardiac Intervention Registry and the Fetal Heart Society is supported by the members and sponsoring institutions. A full listing of contributing centers and sponsors is available at www.ifcir.org and www.fetalheartsociety.org.

Funding Statement: The authors received no specific funding for this study.

Author Contributions: The authors confirm their contributions to the paper as follows: conceptualization: Whitnee Hogan, Anita J. Moon-Grady; writing—original draft preparation: Whitnee Hogan; writing—review and editing: Whitnee Hogan, Thomas S. Przybycien, Anita J. Moon-Grady; supervision: Anita J. Moon-Grady. All authors reviewed and approved the final version of the manuscript.

Availability of Data and Materials: Not applicable. There was no new data presented in this manuscript.

Ethics Approval: Not applicable.

Conflicts of Interest: Anita Moon-Grady is the co-founder and co-leader of the IFCIR and current President of the FHS. The other authors declare no conflicts of interest.

References

1. Moon-Grady AJ, Morris SA, Belfort M, Chmait R, Dangel J, Devlieger R, et al. International fetal cardiac intervention registry: A worldwide collaborative description and preliminary outcomes. J Am Coll Cardiol. 2015;66(4):388–99. [CrossRef].
2. Freud LR, Tworetzky W. Fetal interventions for congenital heart disease. Curr Opin Pediatr. 2016;28(2):156–62. [CrossRef].
3. Friedman KG, Sleeper LA, Freud LR, Marshall AC, Godfrey ME, Drogosz M, et al. Improved technical success, postnatal outcome, and refined predictors of outcome for fetal aortic valvuloplasty. Ultrasound Obstet Gynecol. 2018;52(2):212–20. [CrossRef].
4. Freud LR, McElhinney DB, Marshall AC, Marx GR, Friedman KG, del Nido PJ, et al. Fetal aortic valvuloplasty for evolving hypoplastic left heart syndrome: Postnatal outcomes of the first 100 patients. Circulation. 2014;130(8):638–45. [CrossRef].

5. Callahan R, Friedman KG, Tworetzky W, Esch JJ, Sleeper LA, Lu M, et al. Technical success and serious adverse events for fetal aortic valvuloplasty in a large 20-year cohort. JACC Adv. 2024;3(3):100835. [CrossRef].
6. Maxwell D, Allan L, Tynan MJ. Balloon dilatation of the aortic valve in the fetus: A report of two cases. Br Heart J. 1991;65(5):256–8. [CrossRef].
7. Tworetzky W, Wilkins-Haug L, Jennings RW, Van Der Velde ME, Marshall AC, Marx GR, et al. Balloon dilation of severe aortic stenosis in the fetus: Potential for prevention of hypoplastic left heart syndrome: Candidate selection, technique, and results of successful intervention. Circulation. 2004;110(15):2125–31. [CrossRef].
8. Gómez Montes E, Herraiz I, Mendoza A, Galindo A. Fetal intervention in right outflow tract obstructive disease: Selection of candidates and results. Cardiol Res Pract. 2012;1(1):592403. [CrossRef].
9. Tworetzky W, McElhinney DB, Marx GR, Benson CB, Brusseau R, Morash D, et al. *In utero* valvuloplasty for pulmonary atresia with hypoplastic right ventricle: Techniques and outcomes. Pediatrics. 2009;124(3):e510–8. [CrossRef].
10. Tulzer G, Arzt W, Franklin RCG, Loughna PV, Mair R, Gardiner HM. Fetal pulmonary valvuloplasty for critical pulmonary stenosis or atresia with intact septum. Lancet. 2002;360(9345):1567–8. [CrossRef].
11. Jantzen DW, Moon-Grady AJ, Morris SA, Armstrong AK, Berg C, Dangel J, et al. Hypoplastic left heart syndrome with intact or restrictive atrial septum: A report from the international fetal cardiac intervention registry. Circulation. 2017;136(14):1346–9. [CrossRef].
12. Hogan WJ, Grinenco S, Armstrong A, Devlieger R, Dangel J, Ferrer Q, et al. Fetal cardiac intervention for pulmonary atresia with intact ventricular septum: International fetal cardiac intervention registry. Fetal Diagn Ther. 2020;47(10):731–9. [CrossRef].
13. Furtun BY, Morris SA. Catheter-based fetal cardiac interventions. J Cardiovasc Dev Dis. 2024;11(6):167. [CrossRef].
14. Lowenthal A, Kipps AK, Brook MM, Meadows J, Azakie A, Moon-Grady AJ. Prenatal diagnosis of atrial restriction in hypoplastic left heart syndrome is associated with decreased 2-year survival. Prenat Diagn. 2012;32(5):485–90. [CrossRef].
15. Jacobs JP, Rychik J, Tulzer G, Fouron JC, Maulik D, Tworetzky W, et al. A vision for an international society for fetal and perinatal cardiovascular disease. Curr Opin Pediatr. 2008;20(5):532–7. [CrossRef].
16. Donofrio MT, Rychik J, Moon-Grady AJ, Puchalski MD, Tworetzky W, Cuneo BF, et al. Multidisciplinary collaboration in fetal cardiovascular research: The time has come. J Am Soc Echocardiogr. 2016;29(2):140–2. [CrossRef].
17. Pinto NM, Morris SA, Moon-Grady AJ, Donofrio MT. Prenatal cardiac care: Goals, priorities & gaps in knowledge in fetal cardiovascular disease: Perspectives of the Fetal Heart Society. Prog Pediatr Cardiol. 2020;59:101312. [CrossRef].
18. Abuhamad A, Donofrio MT, Moon-Grady AJ, Rychik J, Puchalski MD, Tworetzky W, et al. The fetal heart society: Facilitating multidisciplinary collaborative fetal cardiovascular research. Prenat Diagn. 2016;36(5):489–91. [CrossRef].
19. Published research—Fetal heart society [Internet]. [cited 2026 Apr 21]. Available from: https://fetalheartsociety.org/published-research/.
20. Board of directors—Fetal heart society [Internet]. [cited 2026 Apr 21]. Available from: https://fetalheartsociety.org/board-of-directors/.
21. Committees—Fetal heart society [Internet]. [cited 2026 Apr 21]. Available from: https://fetalheartsociety.org/committees/.
22. Krishnan A, Jacobs MB, Morris SA, Peyvandi S, Bhat AH, Chelliah A, et al. Impact of socioeconomic status, race and ethnicity, and geography on prenatal detection of hypoplastic left heart syndrome and transposition of the great arteries. Circulation. 2021;143(21):2049–60. [CrossRef].
23. Cohen J, Arya B, Caplan R, Donofrio MT, Ferdman D, Harrington JK, et al. Congenitally corrected transposition of the great arteries: Fetal diagnosis, associations, and postnatal outcome: A fetal heart society research collaborative study. J Am Heart Assoc. 2023;12(11):e029706. [CrossRef].
24. Maskatia SA, Chou FS, Yilmaz B, Howley L, Annavajjhala V, Freud L, et al. Twin and cotwin predictors of fetal demise after laser photocoagulation therapy in advanced stage twin-twin transfusion syndrome: A fetal heart society research collaborative study. J Am Heart Assoc. 2026;15(1):e045070. [CrossRef].

25. Geiger MK, McBrien A, Hornberger LK, Moon-Grady AJ, Madan N, Carvalho JS, et al. Performance of early fetal echocardiography: An expert statement from the fetal heart society. J Am Soc Echocardiogr. 2025;39(2):188–205. [CrossRef].
26. Madan N, Donofrio MT, Szwast A, Moon-Grady AJ, Patel SR, Freud L, et al. Acute maternal hyperoxygenation protocol: Consensus opinion from the Fetal Heart Society. Ultrasound Obstet Gynecol. 2024;64(5):567–73. [CrossRef].
27. Davtyan A, Ostler H, Golding IF, Sun HY. Prenatal diagnosis rate of critical congenital heart disease remains inadequate with significant racial/ethnic and socioeconomic disparities and technical barriers. Pediatr Cardiol. 2024;45(8):1713–23. [CrossRef].
28. Sun HY, Proudfoot JA, McCandless RT. Prenatal detection of critical cardiac outflow tract anomalies remains suboptimal despite revised obstetrical imaging guidelines. Congenit Heart Dis. 2018;13(5):748–56. [CrossRef].
29. Waern M, Mellander M, Berg A, Carlsson Y. Prenatal detection of congenital heart disease—Results of a Swedish screening program 2013–2017. BMC Pregnancy Childbirth. 2021;21(1):579. [CrossRef].
30. Kaur A, Hornberger LK, Fruitman D, Ngwezi DP, Chandra S, Eckersley LG. Trends in the prenatal detection of major congenital heart disease in Alberta from 2008–2018. J Obstet Gynaecol Can. 2022;44(8):895–900. [CrossRef].
31. AIUM Practice parameter for the performance of fetal echocardiography. J Ultrasound Med. 2020;39(1):E5–16. [CrossRef].
32. Hornberger L, Kreeger J, Lee W, Michelfelder E, Morris SA, Peyvandi S, et al. Guidelines and recommendations for performance of the fetal echocardiogram: An update from the American society of echocardiography. J Am Soc Echocardiogr. 2023;36:679–723. [CrossRef].
33. De Robertis V, Stampalija T, Abuhamad AZ, Bosco M, Chaoui R, Formigoni C, et al. Indications for fetal echocardiography: Consensus and controversies among evidence-based national and international guidelines. Ultrasound Obstet Gynecol. 2025;65(6):682–93. [CrossRef].
34. Donofrio MT, Moon-Grady AJ, Hornberger LK, Copel JA, Sklansky MS, Abuhamad A, et al. Diagnosis and treatment of fetal cardiac disease: A scientific statement from the American Heart Association. Circulation. 2014;129(21):2183–242. [CrossRef].
35. Carvalho JS, Axt-Fliedner R, Chaoui R, Copel JA, Cuneo BF, Goff D, et al. ISUOG Practice Guidelines (updated): Fetal cardiac screening. Ultrasound Obstet Gynecol. 2023;61(6):788–803. [CrossRef].
36. Mustafa HJ, Aghajani F, Gurrea IM, Aqeel Z, Khalil A, Abuhamad A, et al. Efficacy of *in-utero* NSAID versus expectant management for fetal severe ebstein anomaly. Am J Obstet Gynecol. 2023;228(1):S317–8. [CrossRef].
37. Freud LR, Wilkins-Haug LE, Beroukhim RS, LaFranchi T, Phoon CK, Glickstein JS, et al. Effect of *in utero* non-steroidal anti-inflammatory drug therapy for severe ebstein anomaly or tricuspid valve dysplasia (NSAID therapy for fetal Ebstein anomaly). Am J Cardiol. 2021;141:106–12. [CrossRef].
38. Park H, Chang CS, Choi SJ, Oh SY, Roh CR. Sirolimus therapy for fetal cardiac rhabdomyoma in a pregnant woman with tuberous sclerosis. Obstet Gynecol Sci. 2019;62(4):280. [CrossRef].
39. Gonçalves MBS, Carvalho MA, Favaro GAG, Mihich JS, Leite JP, Correia De Melo AF, et al. Transplacental sirolimus for reversal of fetal heart failure due to fetal cardiac rhabdomyoma: Fetal and maternal considerations. Fetal Diagn Ther. 2025;52(4):420–8. [CrossRef].
40. Barnes BT, Procaccini D, Crino J, Blakemore K, Sekar P, Sagaser KG, et al. Maternal sirolimus therapy for fetal cardiac rhabdomyomas. N Engl J Med. 2018;378(19):1844–5. [CrossRef].