The Heart Institute, in affiliation with UC San Diego, has made research a major focus, with a mission to conduct high-quality, patient-oriented research. The Institute’s research includes clinical trials, outcomes analysis and evaluation of clinical pathways. We also facilitate basic and translational research, and foster a culture of collaboration to ultimately improve care for those with congenital heart disease.

### Ongoing Heart Institute Research

<table>
<thead>
<tr>
<th>Study Type</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retrospective Chart Reviews</td>
<td>21</td>
</tr>
<tr>
<td>Clinical Trials</td>
<td>11</td>
</tr>
<tr>
<td>Registry/QI Projects</td>
<td>6</td>
</tr>
<tr>
<td>Prospective, Data Collection</td>
<td>11</td>
</tr>
<tr>
<td>Translational Studies</td>
<td>3</td>
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<tr>
<td>HDE Projects</td>
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<tr>
<td>Educational Research Projects</td>
<td>2</td>
</tr>
<tr>
<td>Community Service</td>
<td>1</td>
</tr>
</tbody>
</table>

**Total of 57 studies**

### Upcoming Abstract Deadlines

- **PICS – Miami, FL**: 1/16/17 – 1/19/17  
  **Deadline**: 9/15/16
- **PCICS – Miami, FL**: 12/8/16-12/11/16  
  **Deadline**: 9/19/16
- **ACC – Washington, DC**: 3/17/17 – 3/19/17  
  **Deadline**: 10/18/16
- **ISHLT – San Diego, CA**: 4/5/17 – 4/8/17  
  **Deadline**: 10/25/16
- **IPTA – Barcelona, Spain**: 5/27/17 – 5/30/17  
  **Deadline**: 12/16/16
Extramural Grants in Focus

PHN (Davis): Fontan Udenafil Exercise Longitudinal Trial (FUEL) Randomized, double-blind, placebo controlled Phase 3 clinical trial to evaluate the efficacy and safety of Udenafil versus placebo for the treatment of adolescent subjects who have undergone the Fontan procedure.

RO1 (Nigam): 1) Novel Echocardiography Analysis of Developing Hearts: Echo data will be used to improve the understanding of mechanics of blood flow through the heart. These data will be used to develop and validate computational models of fetal and neonatal ventricular growth. 2) Induced Pluripotent Stem Cell Derived Cardiomyocytes from Congenital Heart Patients to Model Disease: Elucidate the role of biomechanical responsive pathways in the pathogenesis of this severe heart defect and, thereby provide the basis of novel pharmacological treatments for HLHS patients. The focus of this research proposal is to understand the molecular characteristics of HLHS cardiomyocytes and determine how these conditions are altered by various therapies. Induced pluripotent stem cells (IPS cells) are a new platform for studying cardiac diseases, making it possible to grow heart cells from the tissues of patients with different genetic mutations. We seek to create useful models of HLHS to better understand the characteristics of HLHS cardiomyocytes.

Novartis (Singh): Entresto/LCZ696 Phase 2/3 clinical trial: Part 1) Open label single dose study to evaluate safety, tolerability and PK of LCZ696, followed by Part 2) randomized, double blind, parallel group, active controlled study to evaluate safety and efficacy of LCZ696 compared to enalapril. Patients 1 month<18 years of age with heart failure due to systemic left ventricle systolic dysfunction.

Grant Opportunities-Useful Links

Academic Enrichment Fund: Michelle De Guire; mdeguire@ucsd.edu

CTRI(Pilot Projects, Academic-Community, External Funding Opportunities, Pfizer Collaboration Projects: http://ctri.ucsd.edu/funding/Pages/default.aspx

Galvanizing Engineering in Medicine (GEM): http://ctri.ucsd.edu/funding/Pages/GEM-Project.aspx

Frontiers of Innovation Scholar Program: http://research.ucsd.edu/fisp.html Deadline 10/12/2016

American Heart Association: http://my.americanheart.org/professional/Research/FundingOpportunities/FundingOpportunities_UCM_316909_SubHomePage.jsp

NIH Funding: http://www.grants.gov/web/grants/search-grants.html

Recent Intramural Grants

AEF- PI El-Said: The fate of the liver late following Fontan palliation: correlation of non-invasive liver assessment with liver biopsy and with cardiac status as measured by cardiac MRI and by catheterization-obtained hemodynamics.

AEF- PI Frazer, Warfarin Anticoagulation Follow Pediatric Heart Surgery: Limiting Adverse Outcomes, Improving Patient INR Control, Reducing Economic Cost, and Increasing Patient Satisfaction by Comparing Home INR Monitoring to Traditional Lab Monitoring.

AEF- PI Hegde, Evaluating feasibility and usefulness of three dimensional (3D) printed heart models of congenital heart defects.

PDF- PI Perry, MAE Design - Cardio Electrogram Hub: development of a bedside device to integrate atrial and ventricular electrograms with pacing and ECGs, wirelessly.

Academy of Scholars Grant for ACHD Program Development- PI Perry

AEF- PI Yeh, Erythropoietin Can Reduce The Need For Unnecessary Transfusions In Patients With Congenital Cyanotic Heart Disease – A Prospective
Provisional Program:

November 4th  IRB

7:45 to 8am – Christopher Davis, MD, PhD
8am to 8:30 – Jane Burns, MD

November 18th  RCHSD Research/Heart Institute Research

7:45 to 8am – Christine Moran
8am to 8:30 – Review of Current Studies/Open Forum for Research Ideas

December 2nd  Statistics and RCHSD Informatics

7:45 to 8am – James Proudfoot/Andy Richardson
8am to 8:30 – Rakesh Singh, MD, MS

Fellow’s Research Projects

David Aurigemma - Radiofrequency ablation and RVOT stenting in patients with Tetralogy of Fallot/Pulmonary Atresia as an alternative palliation strategy

Mohammad Ebrahim - Measurement of Cardiac output using Impedance cardiography in patients with congenital heart disease

Jesse Lee - Erythropoietin to Prevent Unnecessary Transfusions In Patients with Cyanotic Congenital Heart Disease – A Prospective Randomized Control Trial

Rachel Moore - Studying the role of TBX genes in cardiac development

Jose Silva Sepulveda - Decades of follow up in the Damus-Kaye-Stansel procedure; sudden cardiac death

Annual Research Seminar

November 4th, 18th and December 2nd 2016

Recent Publications


Esophageal bronchus


Esophageal bronchus
Case Reports

Case reports do not require formal review by the RCHSD Privacy Board if written authorization can be obtained from the patient or parent/legal guardian.

Using the Hospital’s standard Authorization for Use of Disclosure of Health Information (Form DT79600)

i. Information on the form must be representative of the case report, specifically noting use as “Other” and stating a case report for publication and/or presentation accordingly.
ii. This form is available in English and Spanish.
iii. This form must be signed by the parent/legal guardian of patients under 18 years of age or by the patient if 18 years of age or older, or in accordance with RCHSD consent policy (e.g., emancipated minor).

New Studies

All new studies will undergo HIRC Pre-IRB review. This process is to:

- Provide scientific review
- Facilitate IRB submission and review for research involving children
- Provide an avenue for researchers to request potential funding

We want to know if you…

- Have a new publication
- Are presenting at a conference
- Have been invited to give a lecture at a national or international conference
- Have been awarded a grant/contract

Please send updates regarding the above to Robyn.

Upcoming Meeting Presentations:

Singh – “I have a gut feeling: The role of the GI system in heart failure” – 4th Pediatric Heart Failure Summit, September 28th