



INTERNATIONAL SOCIETY FOR HEART AND LUNG TRANSPLANTATION

“a Society that includes Basic Science, the Failing Heart, and Advanced Lung Disease”

**ISHLT International Pediatric Heart Failure Registry
Update to the ISHLT Board January 2017**

Update since Sept 2016:

- **As of December 19, 2016 there are 15 (up from 8) centers enrolled/activated with 39 (up from 15) patients entered in the database.**
 - **US 12**
 - **Canada 2**
 - **Brazil 1**
- 2 Steering Committee conference calls
- **Detailed review of the first 6 months of data entry and feedback** received to date from end users. Overall excellent feedback about the data fields and the ease of data entry in the database. List of modifications to the data entry fields compiled and scheduled to be updated in February 2017.
- **Update of Help Documentation** to match modifications to the data entry fields.
- Ongoing promotion and support to assist centers get through the IRB process and enroll in the iPHFR.
- Template **Data Sharing Agreement** with ISHLT (A. Rowe) to streamline process.
- Development and circulation of **Spanish Consent Forms** available on the ISHLT website.
- **Detailed review and update of iPHFR webpages** on ISHLT website – programming in process.
- Promotion of the iPHFR this fall at AHA and PHTS.
- Individual promotional endeavors by Steering committee members.
- Initiation of draft documents for SOPs around data requests and analyses.

Respectfully submitted,

Dr Anne Dipchand, Chair
ISHLT iPHFR Steering Committee