ELSO Registry
Scientific Oversight Committee
UPDATE

Peta MA Alexander MBBS BSc(Hons) FRACP FCICM
Chair, ELSO Registry Scientific Oversight Committee
Medical Lead, Cardiac ECMO
Boston Children’s Hospital and Harvard Medical School
Duties of SOC

- Promote the Scientific Product from the ELSO Registry
- Data Request Review
- Collate Scientific Product from ELSO Registry and identify avenues for as yet under-represented areas of research
- Assist the Registry Chair in coordinating Registry Reports which will be led by experts in the field
- Consider strategies to improve membership survey delivery and completion
- Establish Policies and Procedures around the specified duties to ensure all are carried out with integrity and the highest professional standards
Promote the Scientific Product from the ELSO Registry

Publications referencing ELSO Registry

Search results

Items: 1 to 20 of 281

1. Comparing Percutaneous to Open Access for Extracorporeal Membrane Oxygenation in Pediatric Respiratory Failure.
   PMID: 30080776
   Similar articles

   PMID: 30074247

See more...
Promote the Scientific Product from the ELSO Registry

Publications referencing ELSO Registry
Publications using the ELSO registry

Listed by year of publication

If you do not see a relevant publication please email Dr. Viviane Nasr Viviane.Nasr@childrens.harvard.edu or Dr. Lakshmi Raman Lakshmi.Raman@UTSouthwestern.edu

2018


Promote the Scientific Product from the ELSO Registry

ASAIO Journal. Publish Ahead of Print(); JUL 2018
DOI: 10.1097/MAT.0000000000000863, PMID: 30074497
Issn Print: 1058-2916
Publication Date: 2018/07/25

Highlights from the Extracorporeal Life Support Organization Registry: 2006–2017

Viviane G. Nasr; Lakshmi Raman; Ryan P. Barbaro; Yigit Guner; Joseph Tonna; Kollengode Ramanathan; Pappalardo Federico; Ravi R. Thiagarajan; Peta M.A. Alexander

+ Author Information
ELSO Registry Data Request Review

**ACHIEVEMENTS**

86 ELSO Investigator Proposals Reviewed

8 Data Review Committees

2 Large Dataset Review Committees

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### Data Requests

<table>
<thead>
<tr>
<th>Request Number</th>
<th>Date Completed Request Submitted</th>
<th>PI Request</th>
<th>Age</th>
<th>Study Question</th>
<th>Potential overlapping studies</th>
<th>Comments</th>
<th>Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>1973</td>
<td>10/19/2017</td>
<td></td>
<td></td>
<td>Pregnancy</td>
<td>1727, 1972</td>
<td>Will work with group to formalize extraction criteria.</td>
<td>Yes</td>
</tr>
<tr>
<td>28</td>
<td>11/1/2017</td>
<td></td>
<td>Adults</td>
<td>Solid Organ Transplant (kidney, liver, GI, pancreas)</td>
<td>1927 (which came after this request and was not given)</td>
<td></td>
<td>Accepted</td>
</tr>
<tr>
<td>29</td>
<td>11/3/2017</td>
<td></td>
<td>Adults</td>
<td>To determine the risk factors, predictors, and outcomes of each ischemic and hemorrhagic stroke in patients with each type of ECMO support (ECPR, VA-ECMO, and VV-ECMO).</td>
<td>1766 (not given), Roberto Lorusso research grant, Bembea research grant, 1676 (not given)</td>
<td></td>
<td>Can't approve - can be met with data registry. Group an reconvene. REVISIT PROTOCOL LATER ACCEPTABLE</td>
</tr>
<tr>
<td>30</td>
<td>11/6/2017</td>
<td></td>
<td>Adults</td>
<td>Evaluation of Commonly Used Adult Respiratory Scoring Systems</td>
<td>Potentially many</td>
<td>Would need entire adult pulmonary database</td>
<td>Approved</td>
</tr>
<tr>
<td>31</td>
<td>11/2/2017</td>
<td></td>
<td>Adults</td>
<td>Independent association between pre-ECMO CO2 levels and survival to discharge</td>
<td>Potentially many</td>
<td>Wants an update to the data they already have on this from an ELSO</td>
<td>Approved</td>
</tr>
</tbody>
</table>

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**ELSO Website Publication**
<table>
<thead>
<tr>
<th>Request Number</th>
<th>Date of Data Delivery</th>
<th>Study Question</th>
<th>Age</th>
<th>ECMO Indication</th>
<th>Mode of ECMO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 1903</td>
<td>09/01/2017</td>
<td>Outcome of patients managed on ECMO for arrhythmia</td>
<td>Pediatric</td>
<td>Cardiac and ECPR</td>
<td>VA</td>
</tr>
<tr>
<td>2. 1943</td>
<td>02/06/2018</td>
<td>Mechanical Ventilation Practices in Pediatric VV-ECMO</td>
<td>Pediatric</td>
<td>Respiratory</td>
<td>VV</td>
</tr>
<tr>
<td>3. 1955</td>
<td>02/05/2018</td>
<td>Outcomes of Children with Aspiration Pneumonia requiring ECMO</td>
<td>Pediatric</td>
<td>Respiratory</td>
<td>All</td>
</tr>
<tr>
<td>4. 1957</td>
<td>09/15/2017</td>
<td>The Use of Extracorporeal Life Support in the Emergency Department</td>
<td>All</td>
<td>Cardiac, ECPR, Respiratory</td>
<td>All</td>
</tr>
<tr>
<td>5. 1973</td>
<td>01/29/2018</td>
<td>Outcomes of ECMO in pregnant and peripartum patients</td>
<td>Adults</td>
<td>Cardiac, ECPR, Respiratory</td>
<td>All</td>
</tr>
<tr>
<td>6. 1974</td>
<td>11/15/2017</td>
<td>Outcomes of Extracorporeal Life Support for Solid Organ Transplant Patients who develop Respiratory Failure</td>
<td>Adults</td>
<td>Cardiac, ECPR, Respiratory</td>
<td>All</td>
</tr>
<tr>
<td>7. 1976</td>
<td>11/15/2017</td>
<td>To determine the risk factors, predictors, and outcomes of each ischemic and hemorrhagic stroke in patients with ECMO support</td>
<td>Adults</td>
<td>Cardiac, Respiratory</td>
<td>All</td>
</tr>
<tr>
<td>8. 1978</td>
<td>02/07/2018</td>
<td>Evaluation of Commonly Used Adult Respiratory Scoring Systems</td>
<td>Adults</td>
<td>Respiratory</td>
<td>All</td>
</tr>
<tr>
<td>9. 1980</td>
<td>11/15/2017</td>
<td>Independent association between pre-ECMO CO2 levels and survival to discharge</td>
<td>Adults</td>
<td>All</td>
<td>All</td>
</tr>
<tr>
<td>10. 1992</td>
<td>03/19/2018</td>
<td>Racial Disparities in Outcomes Among Patients on ECMO Support</td>
<td>Adults</td>
<td>All</td>
<td>All</td>
</tr>
</tbody>
</table>
EXTRACORPOREAL LIFE SUPPORT ORGANIZATION

ELSO Scientific Oversight Committee

Duties of SOC

1. Promote the Scientific Product from the ELSO Registry by
   - Ensure reference to ‘ELSO Registry’ in title or abstracts of publications resulting from data analysis of the registry
   - Liaising with the Communications Committee to ensure important studies from the ELSO Registry are highlighted
   - Collating selected publications in a ‘Highlights from ELSO Registry’ review

2. Data Request Review - make recommendations for the release of ELSO Registry data sets on the basis of study question, analysis plan and availability of dataset (i.e., not currently in use by other investigators).

3. Collate Scientific Product from ELSO Registry and identify avenues for as yet under-represented areas of research.
   - Transparency about Data Requests which have been allocated and where Projects are currently outstanding represented on the ELSO website
     [https://www.elso.org/Registry/ApprovedDataRequests.aspx](https://www.elso.org/Registry/ApprovedDataRequests.aspx)

4. Assist the Registry Chair in coordinating Registry Reports which will be led by experts in the field.

5. Consider strategies to improve membership survey delivery and completion.

6. Establish Policies and Procedures around the specified duties to ensure all are carried out with integrity and the highest professional standards.
EXTRACORPOREAL LIFE SUPPORT ORGANIZATION

Phone: (734) 998-6601
FAX: (734) 998-6602

ELSO Scientific Oversight Committee

Membership of SOC

The committee is comprised of voluntary members who represent the breadth of specialty groups who manage ECMO patients and care. The committee will include members representing adult, pediatric and neonatal intensive, surgical, and anesthesia specialties and incorporating representation from across the globe including Europe, Asia Pacific and North America. Previous Chairs of the ELSO Registry and ELSO Registry Scientific Committee will remain honorary members of the SOC.

The committee includes:
- The ELSO Registry Chair
- Chair of the Scientific Oversight Committee
- Members at large

ELSO Registry Scientific Oversight Committee

Peta Alexander
Chair, Scientific Oversight Committee
Staff Physician, Department of Cardiology
ECLS Data Review Committee Agreement

Extracorporeal Life Support Organization

Scientific Committee Data Review Panel
Policy and Agreement

All multi-center data requests will be reviewed by the ELSO Scientific Committee Data Review Panel. A valid review will constitute an assessment by at least 2 members, including at least one present or past Chair of the ELSO Registry or Scientific Review Committee; and Peter Rycus. Following acceptance of a research protocol and data delivery to the investigators, the title of project, principle investigator and data of data delivery will be added to the ELSO Registry website.

In principle and in practice, we will be respectful of other people’s research proposals as brought to us in our capacity as members of the ELSO Scientific Committee Data Review Panel (‘Committee Members’). Specifically, we agree to the points below:

1. Committee Members will keep all proposed study information confidential, including but not limited to center and investigator details, study population and design, planned analysis, target meeting and journal for publication.

2. Committee Members will not use the proposed research to inform our own research.
REQUESTING LARGE ELSO DATASETS FOR PURPOSES OF PUBLICATION

ELSO Registry will release large datasets to investigators for purposes of important research. Release will be based on the impact of the intended research. However, special rules regarding handling, use, and reporting of these data will be enforced.

Definition of “Large Datasets”

Research requests that include large amount of ELSO data (for either study or comparator group) based on examples below as stated below:

- Population: e.g. All pediatric Cases of Respiratory failure
- Indication: e.g. All neonates with Cardiac Indications
- Mode: e.g. All adults with VV ECMO
- Research: e.g. Control population from ELSO data
- Requests deemed by the registry as including large proportion of the registry data
- Any study requiring center specific data for analysis

Note: Large Datasets should RARELY be requested for comparator populations

Additional requirements of Large Datasets Requests

- Research proposal must include investigators from at least 3 centers contributing data to ELSO
  [Rationale: for such large data release, it shouldn’t involve only a single center research team.]
- Each proposal must include the statistician (MS or PhD) who is involved in the project proposal and analysis
  [Rationale: the project proposals worthy of release of large sets of data from ELSO would benefit from the
  input of sophisticated statistical analysis that a specialist in this field should bring]
**ELSO Scientific Oversight Committee Policy Statements:**

*Release of Anonymous Hospital Identifiers*

**Background**

The ELSO Steering Committee has agreed that anonymous hospital identifiers can be considered for release with selected Data Requests. It is essential to provide safeguards for this data in order to protect privacy of individuals and individual institutions. This emphasis on protection ensures that the ELSO Registry’s Data Use Agreement with individual centers is not compromised, and centers continue to contribute patient data with the same expectations of privacy as previously.

**Principles**

1. Investigators are prohibited from releasing, disclosing, publishing or presenting any individually identifying, or individual center identifying information obtained from the anonymous hospital identified data. It is the Principle Investigator’s responsibility to prevent data use violation by anyone who has access to the data.

2. Data violations involving center-level data are of paramount concern to the ELSO Community. If a...