ITR Database Description

• The Intestinal Transplant Registry (ITR) collects data on the international activity & results of intestine transplantation.

• Data collection and the analyses are performed under the direction of the Scientific Committee of the Intestine Transplant Association. Data collection started in April 1985. Analyses and slide sets are only provided to contributing centers.

• A simple, limited core data set is collected to promote reporting. Additional data is collected for specific projects. Participation is voluntary. Data are entered via web forms. Center data is confidential; only aggregate outcomes are reported.
Definitions and Analyses

• Definitions:

<table>
<thead>
<tr>
<th>Transplant Type</th>
<th>Intestine</th>
<th>Liver</th>
<th>Stomach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small Bowel (SBT)</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver/SBT</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Modified MVT</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Full MVT</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

• Pediatric cases defined as < 18 years.

• Graft survival = graft removal or recipient death

• R is used for statistics
Since TRI took over ITR in Spring 2017:

- 45 centers contributed updated data
- 645 transplants

97 Centers with data in ITR (Jan 1985 – Dec 2018)
Global Clinical Experience: Intestinal Tx

(All recipients transplanted between Jan 1985-Dec 2018)

<table>
<thead>
<tr>
<th>Number of Transplants:</th>
<th>4103</th>
</tr>
</thead>
<tbody>
<tr>
<td>SB Alone</td>
<td>1842</td>
</tr>
<tr>
<td>SB+Liver</td>
<td>1251</td>
</tr>
<tr>
<td>MVT</td>
<td>810</td>
</tr>
<tr>
<td>Modified MVT</td>
<td>200</td>
</tr>
<tr>
<td>Current Survivors</td>
<td>2060/4130 (50%)</td>
</tr>
</tbody>
</table>
Global Pediatric Clinical Experience

(All recipients < age 18 years transplanted between Jan 1985 – Dec 2018)

<table>
<thead>
<tr>
<th>Number of Transplants:</th>
<th>2096</th>
</tr>
</thead>
<tbody>
<tr>
<td>SB Alone</td>
<td>728</td>
</tr>
<tr>
<td>SB+Liver</td>
<td>973</td>
</tr>
<tr>
<td>MVT</td>
<td>348</td>
</tr>
<tr>
<td>Modified MVT</td>
<td>47</td>
</tr>
</tbody>
</table>

Current Survivors: 972/2096 (46%)
Regional Intestine Transplant Case Volumes
(All recipients transplanted between Jan 1985-Dec 2018)
Intestinal Transplants Performed
(All recipients transplanted between Jan 1985-Dec 2018)
Intestinal Transplants Performed in the US Compared to UNOS
(All recipients transplanted between Jan 1985-Dec 2018)

![Graph showing the number of intestinal transplants performed in the US compared to UNOS over time from 1990 to 2018. The graph indicates a significant increase in the number of transplants in the late 2000s, with a peak around 2007, followed by a decline in the early 2010s.]
Indications for Transplant

All pediatric recipients transplanted between Jan 1985-Dec 2018, n=2096
Types of Short Gut Diagnoses

All pediatric recipients transplanted between Jan 1985-Dec 2018, n=2096

- Crohn's Disease
- Trauma
- Ischemia
- Intestinal Atresia
- Other
- Necrotizing Enterocolitis
- Volvulus
- Gastrochisis

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Indications for Transplant

All Adult recipients transplanted between Jan 1985-Dec 2018, n=1951

- Short Gut
- Tumor
- Motility Disorder
- Retransplant
- Mucosal Defect

Intestinal Transplant Registry Report © 2019
Types of Short Gut Diagnoses
All Adult recipients transplanted between Jan 1985-Dec 2018, n=1951

- Gastrochisis
- Necrotizing Enterocolitis
- Intestinal Atresia
- Trauma
- Volvulus
- Crohn's Disease
- Ischemia
- Other
Global Trends In Clinical Activity
Pre-Tx Status Over Time
All recipients transplanted between Jan 1985-Dec 2018

**Pediatric, n=2096**

**Adults, n=1951**

- **Home**
- **ICU**
- **Hospitalized**
- **Unknown**
Transplant Type Over Time
All recipients transplanted between Jan 1985- Dec 2018

**Pediatric, n=2096**

**Adults, n=1951**

[Graph showing the percentage of transplant types over time for Pediatric and Adult patients, with bars representing No Liver and Liver Component.]
Re-Transplant Rates
All recipients transplanted between Jan 1985-Dec 2018
Colon Inclusion Over Time
All recipients transplanted between Jan 1985-Dec 2018
Trends in Graft & Patient Survival
Graft Survival by Era

**Pediatric, n=2096**

**Adults, n=1951**

$p < 0.0001$
Adult Graft Survival by Transplant Type (2009-2018)
Adult Patient Survival by Transplant Type (2009-2018)

$p < 0.0001$
Pediatric Graft Survival by Transplant Type (2009-2018)

p < 0.0001
Pediatric Patient Survival by Transplant Type (2009-2018)

p = 0.061
Actuarial Graft Survival Over Time (All Recipients)

One-Year Graft Survival Over Time

Five-Year Graft Survival Over Time

Survival (%)

- Adult
- Pediatric

Transplant Year

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Conditional 5-yr Graft Survival Rates Over Time
(examining only those recipients who survived for at least one year post-transplant)
Causes of Death
Jan 1985 – Dec 2018

Intestinal Transplant Registry Report © 2019
Conclusions
Intestinal Transplants Performed: US vs. UNOS

2018 Registry Report:

2019 Registry Report:
Missing Fields - Major Issues:

• Baseline Intake Form:
  – Total Graft Storage Time
  – Wait time
  – Induction Immunosuppression
  – ABO Compatibility

• Transplant Follow-up Form:
  – Patient Status
  – CMV in last 12 months
  – EBV in last 12 months

• Entire forms are missing for patients:
  – CMV/EBV Serostatus Form
  – Recipient HLA Typing Form
  – Donor HLA Typing Form
  – HLA Antibody Testing Form (@ baseline & follow-up)
Donor Specific Antibodies (DSA)

Pre-Transplant DSA:
- Class I: 27 cases
- Class II: 31 cases

De Novo DSA:
- 139 cases

Post-Transplant DSA Positive Cases:

![Graph showing the number of DSA positive cases over years]

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Moving forward...

- Encourage continuous data entry from registry centers
- "Field Guidelines" document
- Data Quality: DSA, Biopsy, PTLD
- Center dashboards (monthly)
- Regular reporting to Scientific Committee:
  - Address missing fields
Thank you!
Merci!