TRANSFORMing Child Health: Building Statewide Pediatric Research Capacity

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*Trials and ReseArch Networks FOR More
The **ECHO Program** is a $157 million National Institutes of Health (NIH) initiative that aims to understand the effects of environmental exposures on child health and development.

TRANSFORM SC is a statewide network made up of 7 geographically diverse sites (*SC PPRN is a network of 17 sites).

**The goal of the ISPCTN is:**
- provide medically underserved and rural populations with access to clinical trials
- apply findings from relevant pediatric cohort studies to children in IDeA state locations,
- build pediatric research capacity at a national level.

ECHO Infrastructure includes **7 programmatic components**, including the ISPCTN.

For more information about the ECHO program and awardees, visit: [https://www.nih.gov/echo](https://www.nih.gov/echo)
Statewide network

Training and Education

Engagement

Early Network Success

Virtual Clinical Trials Office

Next Steps
Statewide network:
Community practice
Statewide Specialty Practice
Regional Medical Centers
Junior Academic Dept.
Established Academic Dept.
Quick Facts:

• SC is largely rural with 34% living in rural communities compared to 19% nationally.\(^1\)\(^2\)

• SC has a racially diverse population with 27.5% African American, compared to 13.3% in the U.S.\(^3\)

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Some research experience- Heavy clinical load juggling problem

New to research- High level of anxiety and uncertainty

PPRN sites have had variable interventional experience

Strong research base—desire to expand depth/breadth

Research Variability Problem Opportunity
Training and Education:
CITI training/GCP
TRANSFORM webinars
CTSA web-based coordinator training (CCRT)
Face to Face Training
Special Populations panel
Locally produced videos

Statewide network

Virtual Clinical Trials Office

Engagement

Early Network Success

Next Steps
Training and Education

Engagement:
Communications Work Group
Site Visits
PI pairing
Coordinator Calls

Statewide network

Early Network Success

Virtual Clinical Trials Office

Next Steps
Virtual Clinical Trials
Office:
Web-Ex education/training
Statewide eIRB Platform
Network Portal
REDCap e-Consenting
TeleResearch Program
Statewide network
- Operations calls to provide information and discussion
- Site visits from lead study coordinator with local teams

Training and Education
- Face to Face meeting
- Videos
- Mentored “Practice” Discussions

Engagement
- Iterative creation & revision of survey
- On-going Communication Work Group to develop materials

Virtual Clinical Trials Office:
- Web-Ex education/training
- Statewide eIRB Platform
- Network Portal
- REDCap e-Consenting
- TeleResearch Program

Early Network Success

Next Steps
Statewide network

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Next Steps

SC Network Function/Success:
IRB: Cooperative IRB Review- 1st SC network protocol
Research: Statewide Database Enrollment (750+ families with 1100+ children to date)
Who are our TRANSFORMers?
## Characteristics of Families Enrolled in the TRANSFORM Child Health Research Registry ($N = 755$)

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>Number Enrolled</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>488</td>
<td>64.6%</td>
</tr>
<tr>
<td>2</td>
<td>156</td>
<td>20.7%</td>
</tr>
<tr>
<td>3</td>
<td>75</td>
<td>9.9%</td>
</tr>
<tr>
<td>4</td>
<td>30</td>
<td>4.0%</td>
</tr>
<tr>
<td>5</td>
<td>6</td>
<td>0.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Race/Ethnicity</th>
<th>Number Enrolled</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic White</td>
<td>330</td>
<td>43.7%</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>292</td>
<td>38.7%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>77</td>
<td>10.2%</td>
</tr>
<tr>
<td>Other</td>
<td>46</td>
<td>6.1%</td>
</tr>
<tr>
<td>Non-disclosed</td>
<td>7</td>
<td>0.9%</td>
</tr>
<tr>
<td>Biracial</td>
<td>3</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>South Carolina Region</th>
<th>Number Enrolled</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upstate</td>
<td>561</td>
<td>74.3%</td>
</tr>
<tr>
<td>Midlands</td>
<td>105</td>
<td>13.9%</td>
</tr>
<tr>
<td>Low Country</td>
<td>71</td>
<td>9.4%</td>
</tr>
<tr>
<td>Pee Dee</td>
<td>18</td>
<td>2.4%</td>
</tr>
</tbody>
</table>
### Characteristics of Children Enrolled in the TRANSFORM Child Health Research Registry (N = 1,175)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number Enrolled</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>595</td>
<td>50.6%</td>
</tr>
<tr>
<td>Female</td>
<td>579</td>
<td>49.3%</td>
</tr>
<tr>
<td>Not available</td>
<td>1</td>
<td>0.1%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2 Years</td>
<td>288</td>
<td>24.5%</td>
</tr>
<tr>
<td>3-5 Years</td>
<td>214</td>
<td>18.2%</td>
</tr>
<tr>
<td>6-11 Years</td>
<td>403</td>
<td>34.3%</td>
</tr>
<tr>
<td>12-18 Years</td>
<td>256</td>
<td>21.8%</td>
</tr>
<tr>
<td>Over 18 Years</td>
<td>3</td>
<td>0.3%</td>
</tr>
<tr>
<td>Not available</td>
<td>11</td>
<td>0.9%</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>504</td>
<td>42.9%</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>437</td>
<td>37.2%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>153</td>
<td>13.0%</td>
</tr>
<tr>
<td>Other</td>
<td>72</td>
<td>6.1%</td>
</tr>
<tr>
<td>Non-disclosed</td>
<td>9</td>
<td>0.8%</td>
</tr>
</tbody>
</table>
Family Level Interests

Transform Registry - Parent Identified Child Health Interests

- ADHD/School Problems: 55.6%
- Autism/Developmental Disorders/Epilepsy: 54.3%
- Maternal/Child Health & Genetic Disorders: 37.4%
- Sleep Issues: 31.3%
- Depression/Anxiety: 26.9%
- Asthma/Respiratory Infections/Smoking: 28.5%
- Endocrine/Weight Disorders: 26.9%

Percent of SC Families Who Agree
Family Level Interests by Race and Ethnicity
TRANSFORM SC

Statewide network

Training and Education

Engagement

SC Network Function Success

Virtual Clinical Trials Office

Next Steps: Partner, partner, partner!
Thanks to my co-PIs (Andy and Lisa) and our lead Coordinator (Sarah Newman-Norlund)—we couldn’t have a better team!

Questions?
Thank you!
How the Registry Works

- Go to www.transformsc.org
- Click on the “Be a Hero for Kids” Button
- Complete the Registry either for your family or as a Fake entry (type “Fake” as first name)
- SITE CODE: not needed