Disclosures

• Recipient - 2014 NAPNAP Foundation Research Grant

• Research Coordinator - NIH-funded U01 - NIDDK 2U01DK084538-06 - “Continuation of the Children’s Hospital LA ChiLDReN Liver Research Center”
CSHCN
“Those who have, or are increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”

http://mchb.hrsa.gov/research/strategic_definitions.asp
Objectives

1. Identify needs
2. Describe disaster preparations
3. Discuss the Emergency Information Form
Have you been directly affected by a disaster?
Have your patients been affected by disaster?
Have your patients been affected by disaster?
Are my patients and families prepared?
Anatomical Differences

- NO Hair
- Big Head
- Little Head
- Hair
Developmental Differences
technology-dependent power access planning
Meet Pedro
Trento 2014

needs home

parenteral

emergencies health both preparedness comprehensive

disaster plan providers services

risk strike Individuals notice service power

met Creating Natural ensure disasters electricity

care consumer moment's especially vulnerable

serious other chronic assist

delivery imperative nutrient

depend clean planning
## Assessment for Patient Risk

<table>
<thead>
<tr>
<th>Risk Level</th>
<th>Needs Assessment</th>
<th>Therapy Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>High risk/priority</td>
<td>• Uninterrupted services&lt;br&gt;• Life-sustaining equipment&lt;br&gt;• Regularly scheduled RN visits</td>
<td>• Inotropes&lt;br&gt;• Ventilator dependent&lt;br&gt;• Oxygen dependent&lt;br&gt;• Lack of caregiver&lt;br&gt;• Complex wound care</td>
</tr>
<tr>
<td>Medium risk/priority</td>
<td>• No immediate threat to life&lt;br&gt;• Possible adverse effect if homecare service interrupted</td>
<td>• HPEN&lt;br&gt;• Pain management&lt;br&gt;• IV hydration</td>
</tr>
<tr>
<td>Low risk/priority</td>
<td>• No major adverse effect if homecare services interrupted</td>
<td>• IV antibiotics&lt;br&gt;• Caregiver available</td>
</tr>
</tbody>
</table>

Trento & Allen, 2014
## Levels of Basic Preparedness

<table>
<thead>
<tr>
<th>Basic Preparedness Indicators</th>
<th>Present Study</th>
<th>APHA</th>
<th>NCDP</th>
<th>CCPR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency supply kit</td>
<td>19.6</td>
<td>21</td>
<td>31</td>
<td>36</td>
</tr>
<tr>
<td>Family emergency communication plan</td>
<td>9</td>
<td>17</td>
<td>43</td>
<td>63</td>
</tr>
<tr>
<td>3 day supply stored water</td>
<td>11.2</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>3 day supply sustainable food</td>
<td>52.4</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Copy of child’s medical emergency plan</td>
<td>24.1</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
</tbody>
</table>

Baker & Baker, 2010
# Factors for Noncompletion of Tasks

<table>
<thead>
<tr>
<th>Indicator</th>
<th>No; unspecified</th>
<th>No need to do now</th>
<th>Want to but don’t know how</th>
<th>Hard to complete task</th>
<th>Done in past not updated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family communication plan</td>
<td>5.5</td>
<td>3.4</td>
<td>57.9</td>
<td>16.6</td>
<td>7.6</td>
</tr>
<tr>
<td>Emergency supply kit</td>
<td>8.4</td>
<td>2.1</td>
<td>39.2</td>
<td>23.8</td>
<td>7.0</td>
</tr>
<tr>
<td>3 day supply water</td>
<td>8.4</td>
<td>7.4</td>
<td>30.1</td>
<td>28.7</td>
<td>14.7</td>
</tr>
<tr>
<td>3 day supply food</td>
<td>9.7</td>
<td>2.1</td>
<td>14.5</td>
<td>17.9</td>
<td>3.5</td>
</tr>
<tr>
<td>Copy of child’s medical plan</td>
<td>9.7</td>
<td>6.2</td>
<td>42.8</td>
<td>13.1</td>
<td>4.1</td>
</tr>
</tbody>
</table>

Baker & Baker, 2013
### Dependence on Electrical Devices

<table>
<thead>
<tr>
<th>Device</th>
<th># Patients Using Device</th>
<th># Instances Battery Backup</th>
<th># Instances Most Important for Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeding pump</td>
<td>40</td>
<td>27</td>
<td>18</td>
</tr>
<tr>
<td>Albuterol nebulizer</td>
<td>36</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Pulse oximeter</td>
<td>25</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Suction machine</td>
<td>23</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>O2 concentrator</td>
<td>17</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Ventilator</td>
<td>11</td>
<td>6</td>
<td>10</td>
</tr>
</tbody>
</table>

Additional items reviewed: chest vest, cough assist device, humidifier, peritoneal dialysis, electric wheelchair

Sakashita et al 2013
“Most Important” Device

<table>
<thead>
<tr>
<th>Feature</th>
<th>Ventilator</th>
<th>Oxygen Concentrator</th>
<th>Feeding Pump</th>
<th>Other Devices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most important</td>
<td>10</td>
<td>7</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>Has battery back up</td>
<td>6</td>
<td>3</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Battery power 5-24 hrs</td>
<td>3</td>
<td>5</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Battery power 1-5 days</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Survival 1 hour or less if device fails</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Backup plan for prolonged power loss</td>
<td>8</td>
<td>2</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Car converter for device power</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Has electrical generator</td>
<td>6</td>
<td>2</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

Sakashita et al 2013
IR Disaster Preparedness

Goodhue et al unpublished data

- Copy EIF
- Additional supplies for pump
- Back up nutrition
Putting It All Together
ABC’s of Disaster Planning for CSHCNs

• Assess vulnerabilities
  – Disaster risk
  – Type of special needs

• Build a plan (use EIF)

• Conduct a drill
Other Family Members
Family
Pets
R U Prepared?
Additional Learning?

Blessman et al 2007
Healthcare Worker Constructs

• ABILITY

• WILLINGNESS

Qureshi et al 2005
Willingness to Respond in a Disaster: A Pediatric Nurse Practitioner National Survey

Catherine J. Goodhue, MN, RN, CPNP, Rita V. Burke, PhD, MPH, Rizaldy R. Ferrer, PhD, Nikunj K. Chokshi, MD, Fred Dorey, PhD, Jeffrey S. Upperman, MD, FAAP, FACS

Published Online: February 21, 2011
8% have military experience
0.9% had combat experience
22% have specified role in work disaster plan
56% not sure of role/22% do not have role

Goodhue et al 2011
29% have personal/family disaster plan
29% have disaster kit
34% have disaster experience
55% have disaster preparedness training

Goodhue et al 2011
Summary

- Prepare your home
- Prepare your family
- Prepare your office
- Prepare your patients

Thank you
REFERENCES


<table>
<thead>
<tr>
<th>References</th>
<th>Title</th>
</tr>
</thead>
</table>


RESOURCES

• American Red Cross
  – http://www.redcross.org/prepare/location/home-family/disabilities

• Emergency Survival Program
  – www.espfocus.org

• Federal Emergency Management Agency
  – www.fema.gov

• National Organization on Disabilities
  – http://nod.org/research_publications/emergency_preparedness_materials/for_people_with_disabilities

• Pediatric Disaster Resource and Training Center (CHLA)
  – www.chladisastercenter.org