Reducing Time from Referral to Treatment: Strengthening the Weak Links in the Newborn Screening Chain of Events

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Newborn Screening Program
WA CF NBS Algorithm

• IRT/IRT

• In-house F508del if:
  – LBW and/or clinically unstable and persistently elevated IRT
  – IRT > 150 ng/mL on 1st screen or persistently elevated IRT and family/clinic is non-compliant
WA CF NBS Follow-Up: SwCl Referral

- DOH to PCP: phone & fax
  - memo
  - requisition form
  - CF sweat lab info
  - CF general overview

- PCP to Family: notification
- Family to Sweat lab: schedule
- Sweat lab to CF clinic: results

1-2d to 1d
WA CF NBS Follow-Up: Abnormal Results

We monitor:
- Date of birth
- Birthweight
- Race
- Sex
- NICU status
- IRT value
- Age at collection

If referred for a sweat test, we also monitor:
- SwCl facility
- Date of referral
- Date of resolution
- QNS results
WA CF NBS Follow-Up: True Positives

We monitor...

- Date of birth
- Birthweight
- IRT value
- Age at collection
- Race
- Sex
- SwCl value
- Date of diagnosis
- Date of 1st clinic visit
- Genotype
- Pancreatic status
- Meconium ileus
- CF center
# Timeline of Infants Diagnosed with CF 2012 –2013

<table>
<thead>
<tr>
<th>Age at reporting 1st elevated IRT</th>
<th>Age at collection of 2nd NBS</th>
<th>Age at referral</th>
<th>Age at SwCl</th>
<th>Age at 1st clinic visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 days (median)</td>
<td>9 days (median)</td>
<td>19 days (median)</td>
<td>24 days</td>
<td>28 days</td>
</tr>
</tbody>
</table>

5 days

4 days
SwCl Referrals by Time between Referral and 1st SwCl

Retrospective secondary data analysis
January 2011 – December 2013
Non- NICU infants requiring sweat testing
Stratified by CF Center
SwCl Referrals by Time between Referral and 1\textsuperscript{st} SwCl (n=86)

Interval time between referral and 1\textsuperscript{st} SwCl

- 1-2 days
- 3-7 days
- 8-14 days
- 15-30 days
- 31+ days

WA CF Center 1
WA CF Center 2
WA CF Center 3
# Timeline for Newborns Referred for SwCl – Median Days

<table>
<thead>
<tr>
<th>Event</th>
<th>Median Days (n)</th>
</tr>
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<tbody>
<tr>
<td>Days from referral to 1&lt;sup&gt;st&lt;/sup&gt; SwCl</td>
<td>4 (n=86)</td>
</tr>
<tr>
<td>Days from positive SwCl to 1&lt;sup&gt;st&lt;/sup&gt; clinic visit</td>
<td>3 (n=25)</td>
</tr>
<tr>
<td>Days from referral to resolution</td>
<td>5 (n=85)</td>
</tr>
<tr>
<td></td>
<td>All WA CF Centers</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------------</td>
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### Timeline for Newborns Referred for SwCl – Median Days

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<tr>
<td></td>
<td>4 (n=86)</td>
<td>4.5 (n=52)</td>
<td>2 (n=21)</td>
<td>12 [range 1-25] (n=13)</td>
</tr>
<tr>
<td><strong>Days from positive SwCl to 1&lt;sup&gt;st&lt;/sup&gt; clinic visit</strong></td>
<td>3 (n=25)</td>
<td>3 (n=17)</td>
<td>4 (n=6)</td>
<td>1.5 (n=2)</td>
</tr>
<tr>
<td><strong>Days from referral to resolution</strong></td>
<td>5 (n=85)</td>
<td>5 (n=52)</td>
<td>3 (n=21)</td>
<td>10 [range 1-194] (n=12)</td>
</tr>
</tbody>
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Quantity Not Sufficient (QNS) Results

- 10% (n=12) of newborns sweat tested had QNS results
- 6 cases (50%) with QNS results were diagnosed with CF (all dx by DNA)
- ALL true positive cases with QNS results had at least 1 copy of F508del
- The median time between the 1st QNS result and 1st repeat sweat test is 24 days (n=6)
CF Center Outreach Efforts

CF Center 1
- CF Center & lab staff education
- PCP education

CF Center 2
- What are their processes?
  - Daily sweat test openings
  - Multiple locations

CF Center 3
- Change in sweat test scheduling
- Evaluation of sweat collection methods
Changes in NBS Follow-Up

• Tighter follow-up for referrals

• In-house test for F508del after QNS result

• PCP education on sweat testing
Next Steps: Evaluation

In progress!
Final Thoughts

✓ Relationship with NBS clinical consultants

✓ Consistent surveillance of abnormal results

✓ Applicable to follow-up of other NBS disorders!
Thank You!

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Come visit our lab!