Developing and Maintaining Parent Fact Sheets for Newborn Screening: A Decade of Multi-State Collaboration

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Overview

- The Who/Why/What/How of the parent fact sheets
- Experience over the past decade of maintaining the fact sheets and developing new ones
- Where do we go from here?
Multi-State Collaborative Project
(the Who from the Beginning)

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Multi-State Collaborative Project (the Who Now)
Why Fact Sheets?

✦ Result of a Health Resources and Services Administration funded project that asked parents what they needed if newborn screening is expanded to detect many more disorders.

✦ Parents (and primary care providers) wanted accurate and timely information about the possible disorder especially if the number of possible disorders increases.

✦ Developed for parents searching for information between call from primary care provider and consultation with specialist.
What are the Parent Fact Sheets?

- Initially developed fact sheets only for the new disorders detected through tandem mass spectrometry.

- Drafted by genetic counselors at the 7-8th grade reading level.

- Reviewed by specialists, primary care providers, and parents of children with the disorder described in the fact sheet.

- Revised based on feedback.
What are the Parent Fact Sheets?

- Available on website (www.newbornscreening.info) or downloadable in PDF.
- Added Spanish fact sheets based on regional need.
- Fact sheets are copyright free. We only request that acknowledgement of source and website is referenced so families can have the most current version of the fact sheet.
Maintaining the Parent Fact Sheets

- Fact sheets are reviewed and updated every two years.
- Genetic counselor does update and the updates are reviewed by the specialists in the region.
- Additional review is requested by specialists outside of the region if we need additional expertise.
- Updated fact sheet is posted on website with “last update date” revised.
New fact sheets are developed when most of the region is adding a new disorder to their NBS panel.

New fact sheets are also developed for special cases such as for Alaska families with newborn screening results indicating CPT1a Arctic Variant.

Process is generally the same as when we started developing the fact sheets.
What has happened?
Some numbers…

Number of Hits

- 2006*
- 2007
- 2008
- 2009
- 2010
- 2011
- 2012
- 2013
- 2014**

* Data lost before 2006
** Data up to 9/30/2014
Some numbers...

Number of Unique Visitors

- 2006
- 2007
- 2008
- 2009
- 2010
- 2011
- 2012
- 2013
- 2014

Number of Unique Visitors

* Data lost before 2006
** Data up to 9/30/2014
Some numbers...

Number of Page Views

2006*
2007
2008
2009
2010
2011
2012
2013
2014**

A Web page that has been viewed by one visitor.

* Data lost before 2006
**Data up to 9/30/2014
Some numbers…

How do people find the fact sheets?

- **Search Engine**
- **Direct to website by typing in URL or bookmark**

* Data up to 9/30/2014

* Data lost before 2006

**Data up to 9/30/2014**
Where users come from:

- United States
- Canada
- United Kingdom
- Spain
- Mexico
### What Has It Cost?

#### Major Cost

<table>
<thead>
<tr>
<th>Other Costs*</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic Counselors’ work</td>
<td>$4000/year</td>
</tr>
<tr>
<td>Website hosting</td>
<td>$100/year</td>
</tr>
</tbody>
</table>

* Does not include in-kind cost of:
- Hawaii Department of Health staff time (Project Director, technical assistant, clerk)
- Reviewers (NBS program staff, metabolic specialists, families)
What Have We Learned In Ten Years?

- Very positive response to fact sheets from both families and providers.
- Must develop routine to update fact sheets.
- Maintaining the Spanish versions of the fact sheets is very difficult.
- Finding the right people to work on the fact sheets has been interesting.
- Additional literature reviews will not capture what is not published.
What Have We Learned In Ten Years?

- Experts always request more technical language which would raise the reading level.
- Working collaboratively for so long has helped figure out how to get to “comfortable” consensus on information provided.
- The long term experience makes developing new fact sheets a lot easier.
- Return on Investment is high.
## Work Estimate

**Adding New Parent Fact Sheets**

To develop one new fact sheet:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review of literature, 1&lt;sup&gt;st&lt;/sup&gt; draft with graphics</td>
<td>15-20 hours</td>
</tr>
<tr>
<td>Review by experts &amp; revisions</td>
<td>4 weeks</td>
</tr>
<tr>
<td>Parent reviews and revisions</td>
<td>4 weeks</td>
</tr>
<tr>
<td>Final draft</td>
<td>1 hour</td>
</tr>
<tr>
<td>Post to website with printable version and final website check</td>
<td>1 hour</td>
</tr>
</tbody>
</table>
Do the Parent Fact Sheets Help?

“Our daughter had VLCADD and recently passed away. The doctors said they knew very little about the condition ....This fact sheet has been a real lifeline and answered many of our questions. It was very clear and easy to understand, and has been invaluable to us in helping our family understand this condition.”
Do the Parent Fact Sheets Help?

“Thank you for your hard work and contribution to these children's cause. I hope you and your team realize that your efforts have helped not only those children and families in your area struggling with FODs, but families half a world away.”
“First, let me say THANK YOU!!!! This sheet is fantastic. I wish I could have given it to our first metabolic doctor...I will also be giving this fact sheet to the school board to help them understand my daughter’s illness. I will definitely recommend this fact sheet to parents/doctors/nurses/educators!”
Mahalo..

To the many parents, staff, specialists, primary care providers, and public health professionals that have been part of this journey for the past decade.

Onto the next 10 years...