



# Western States Genetic Services Collaborative

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

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[www.newbornscreening.info](http://www.newbornscreening.info)



Expanded Newborn Screening using Tandem Mass Spectrometry  
Financial, Ethical, Legal and Social Issues (FELSI)



# 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)

## **Thalia Wood**

Alaska Department of Health & Social Services

## **George Cunningham, Kathleen Velazquez & Norah Ojeda**

California Department of Health Services

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Hawaii Department of Health

## **Anne Spencer**

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Oregon State Public Health Laboratory

## **Judi Tuerck**

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## **Santosh Shaunak & Jana Pruski-Clark**

Washington State Department of Health

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Kaiser Permanente Center for Health Research

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## **Barbara Pettersen**



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# Multi-State Collaborative Project (the Who Now)



Western States Genetic Services Collaborative



# 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 7-8<sup>th</sup> 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](http://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.

A photograph of a man with dark hair, wearing a white t-shirt, holding a baby in his arms. The man is looking towards the camera with a slight smile. The baby is wearing a grey and white striped onesie. The background is a textured, light-colored wall.

# 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.



# Developing New Parent Fact Sheets?



- 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.

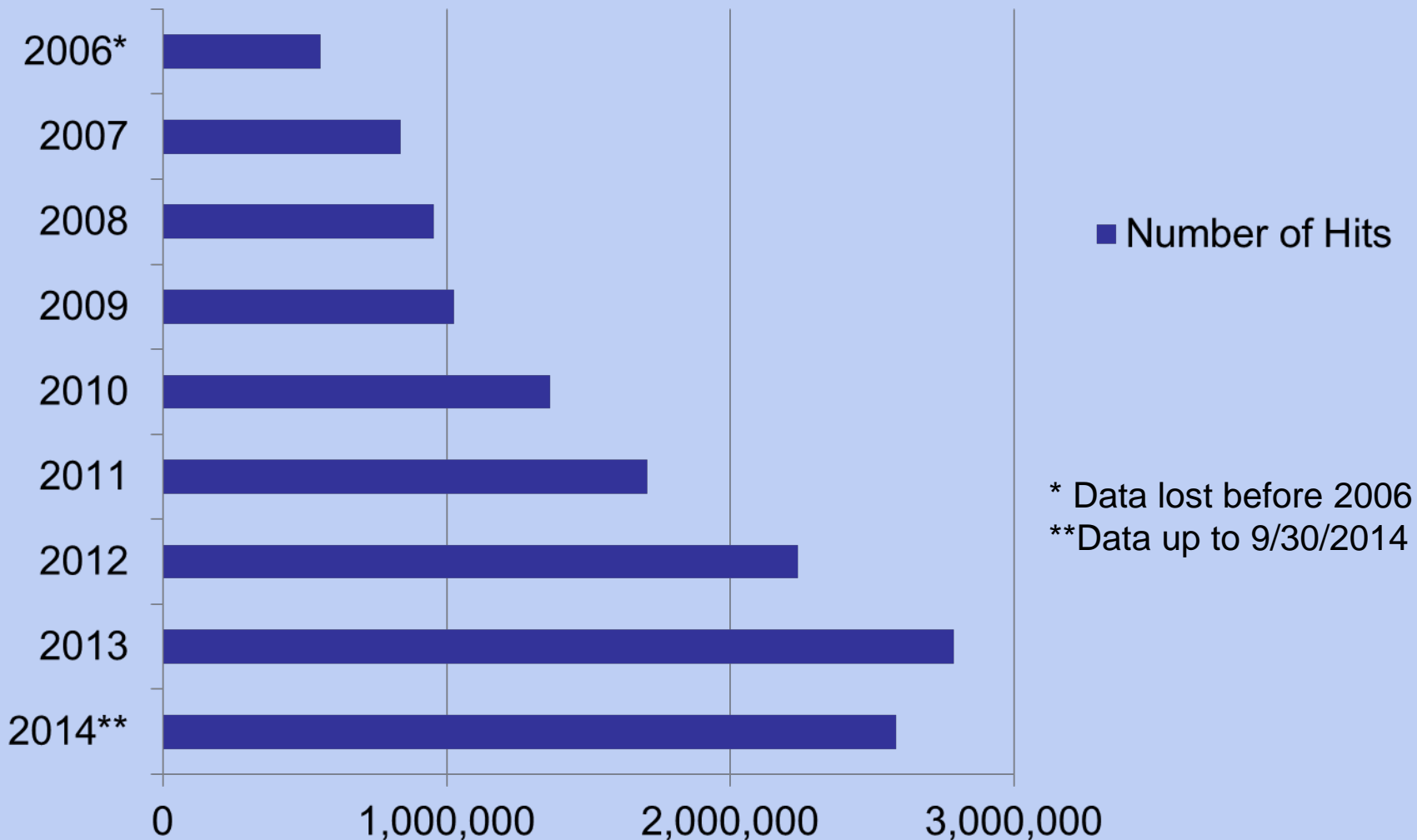
# What has happened?





# Some numbers...

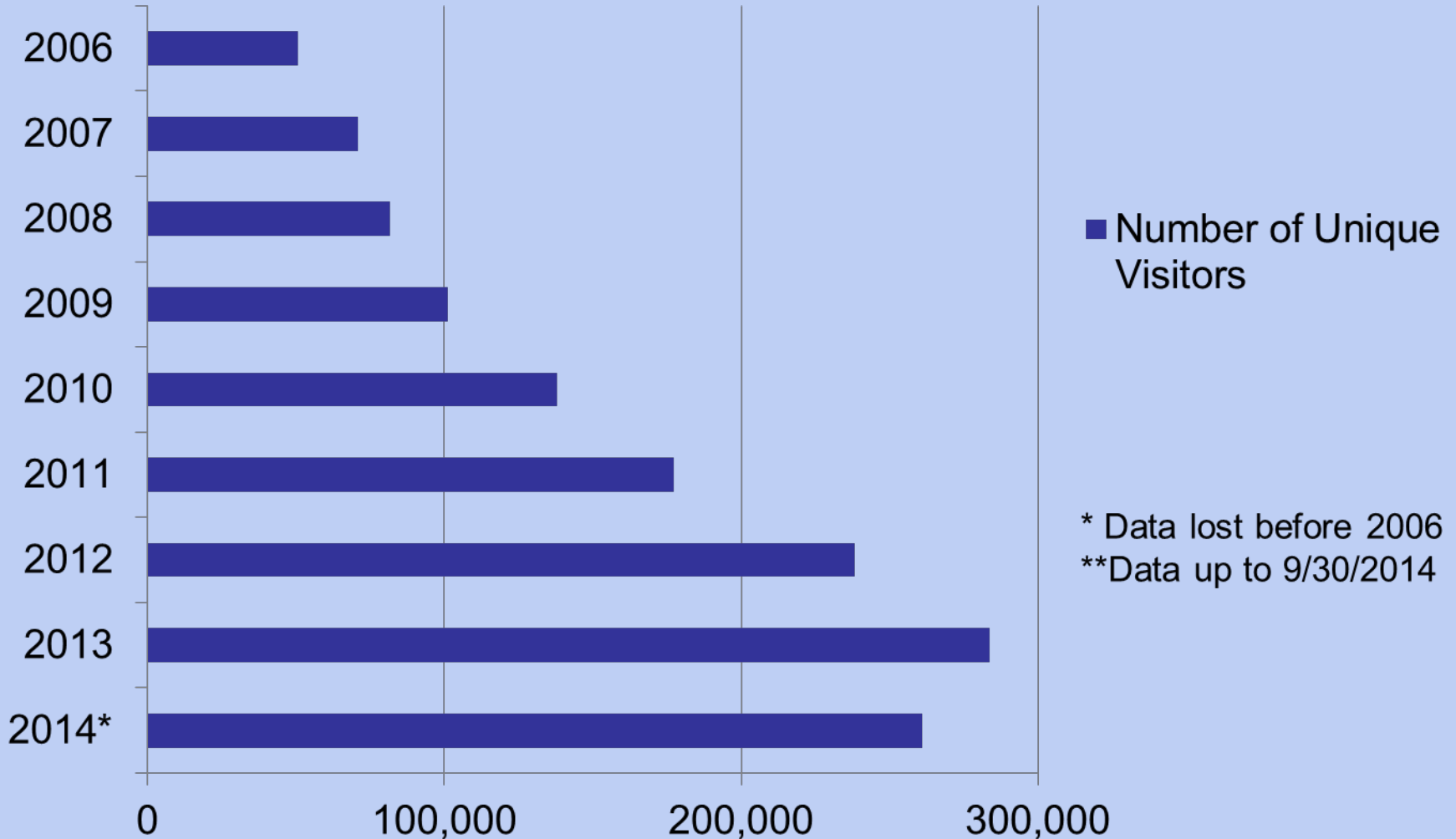
## Number of Hits



# Some numbers...



## Number of Unique Visitors

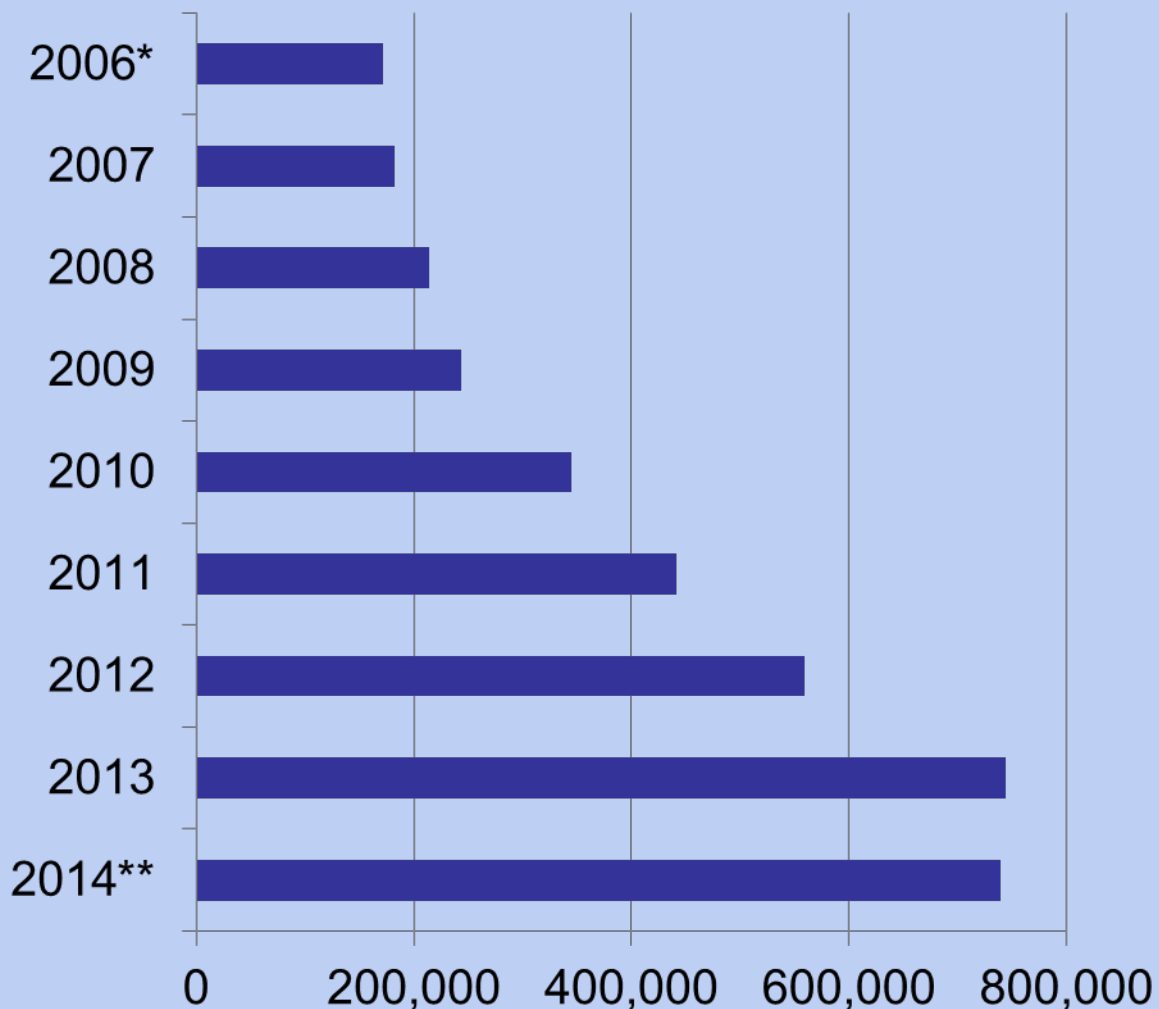






# Some numbers...

## Number of Page Views



■ Number of Page Views

A Web page that has been viewed by one visitor.

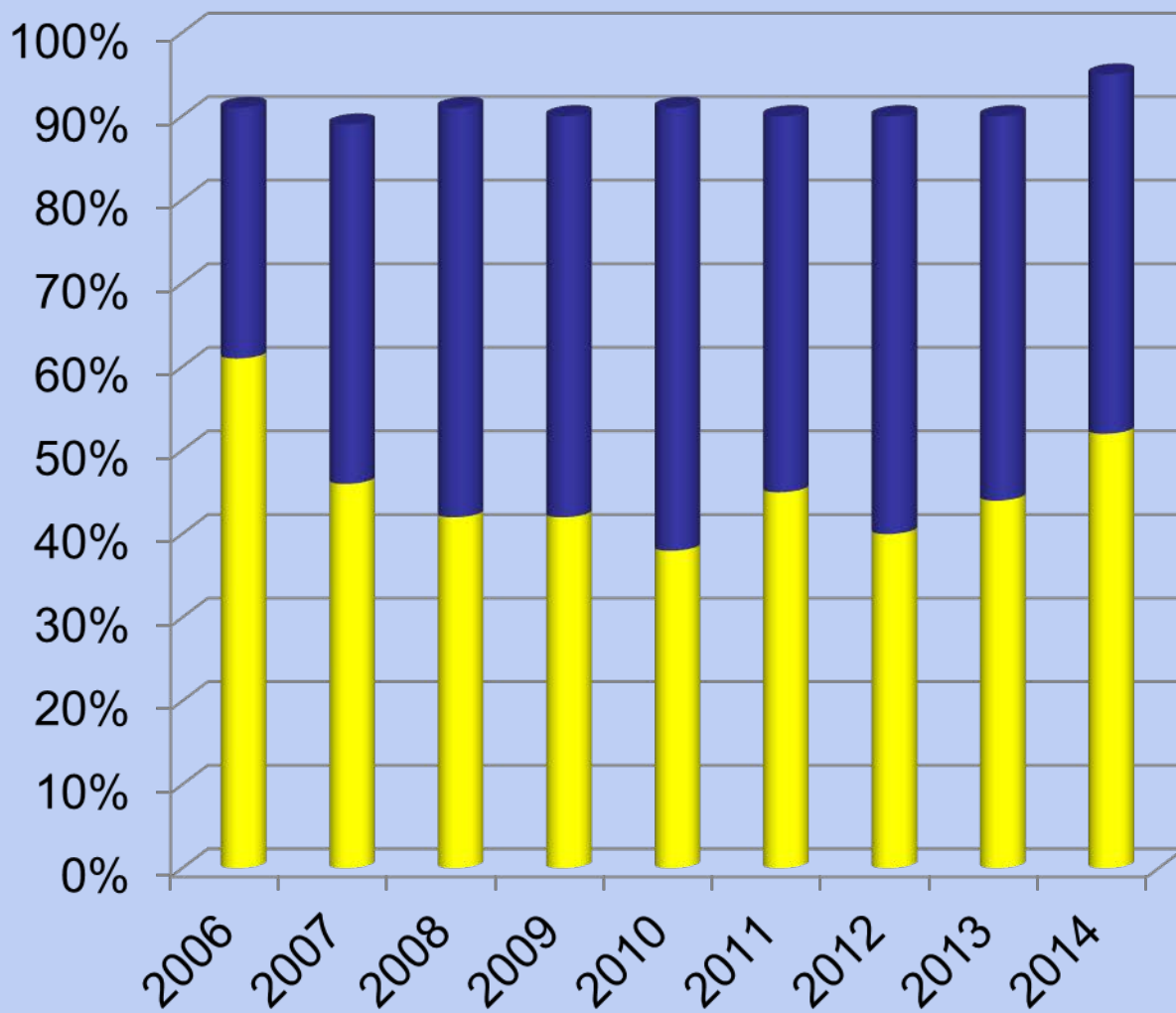
\* Data lost before 2006

\*\*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



# Some numbers...

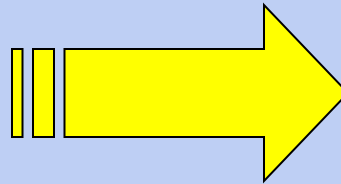
Where users come from:

- ❖ United States
- ❖ Canada
- ❖ United Kingdom
- ❖ Spain
- ❖ Mexico



# What Has It Cost?

Major Cost



**TIME**

Other Costs*	
Genetic Counselors' work	\$4000/year
Website hosting	\$100/year

\* 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.

# Adding New Parent Fact Sheets

## Work Estimate



### To develop one new fact sheet:

Review of literature, 1 <sup>st</sup> draft with graphics	15-20 hours
Review by experts & revisions	4 weeks
Parent reviews and revisions	4 weeks
Final draft	1 hour
Post to website with printable version and final website check	1 hour

# 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.”

# Do the Parent Fact Sheets Help?

- ❖ “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...*