

# EVALUATING AND IMPLEMENTING CHANGE IN FOLLOW-UP

SARA DENNISTON, BS

OREGON STATE PUBLIC HEALTH LAB



# ABOUT ME

Started 4/1/2013

hired out of Medicaid/Health department-internal state employee

Hired with little knowledge of NBS and the entire system

Trained by Judi Tuerk

Goals for once I was comfortable with Follow up in general (which took about a full year):

- correspondence edits
- complete database capabilities
- Streamline inner office processes to reduce wasted time and materials



# LETTERHEAD



PUBLIC HEALTH DIVISION  
OREGON STATE PUBLIC HEALTH LABORATORY

John A. Kitzhaber, MD, Governor

Oregon  
Health  
Authority

P.O. Box 275  
Portland, OR 97207-0275  
Desk: 503-693-4174  
Fax: 503-693-5601  
TTY: 971-673-0372



PUBLIC HEALTH DIVISION  
Oregon State Public Health Laboratory - Newborn Screening

John A. Kitzhaber, MD, Governor


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# ONS/ INSUFFICIENT BLOOD NOTIFICATION

## ORIGINAL



PUBLIC HEALTH DIVISION  
OREGON STATE PUBLIC HEALTH LABORATORY  
John A. Kitzhaber, MD, Governor



P.O. Box 275  
Portland, OR 97207-0275  
Desk: 503-693-4174  
Fax: 503-693-5601  
TTY: 971-673-0372

### URGENT FOLLOW UP REQUESTED

July 3, 2014  
FAX: 503-693-5601

Dear Dr. Jacobs,

Below is a copy of the **FIRST** newborn screening specimen form submitted to the Oregon Public Health Lab, Newborn Screening section. The specimen submitted was unsatisfactory due to: **Insufficient Blood for All Tests.**

Because many of the disorders screened for can be life threatening, it is very important for you to contact the family immediately for a redraw. The family should have been given the second part of the newborn screening kit in the hospital. Please use this kit for the redraw and it will also suffice as the routine second newborn screening specimen. In the event the repeat screen is collected before 10 days of age, another newborn screening kit will be sent to you, upon your request. If you have any questions please do not hesitate to call me.

Sara Denniston, BS  
Newborn Screening Follow-Up Coordinator

Specimen Number:  OR  \* 0 1 0 5 0 0 6 3 0 0 \*

Baby's Last Name:  Baby's First Name:  Birth Date:  Time of Day (circle one):  Birth Wt.:  Lbs.  Oz.

Specimen Date:  Time of Day (circle one):  Present Wt.:  Lbs.  Oz.

Sex:  M  F  ID Chart #:

Food Source Last 24 Hours:  Breast  Soy Formula  NPO  Other

Other Factors:  Jaundice  Feeding  Other

Transfusion:  Yes  No

Hyperinflation:  Yes  No

Mother's Address-Number & Street:

City:  State:  Zip Code:

Telephone Number:


Send Report to PCP/Clinic:  CODE:

Address/Telephone Number:


Original ACN (For Lab Use Only):

Specimen taken by:

## UPDATED



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Fax: 503-693-5601  
TTY: 971-673-0372

### NEWBORN SCREENING URGENT FOLLOW UP REQUESTED

June 9, 2014  
FAX: 503-693-5601

The **FIRST** newborn screening specimen submitted was unsatisfactory due to: **Insufficient Blood for All Tests.**

**ACTION NEEDED:**  
The family should have been given the second part of the newborn screening kit in the hospital. Use this kit for redraw ASAP.  
If further instruction is needed we will contact you.

Sara Denniston, BS  
Newborn Screening Follow-Up Coordinator

Specimen Number:  OR  \* 0 1 0 5 0 0 6 3 0 0 \*

Baby's Last Name:  Baby's First Name:  Birth Date:  Time of Day (circle one):  Birth Wt.:  Lbs.  Oz.

Specimen Date:  Time of Day (circle one):  Present Wt.:  Lbs.  Oz.

Sex:  M  F  ID Chart #:

Food Source Last 24 Hours:  Breast  Soy Formula  NPO  Other

Other Factors:  Jaundice  Feeding  Other

Transfusion:  Yes  No

Hyperinflation:  Yes  No

Mother's Address-Number & Street:

City:  State:  Zip Code:

Telephone Number:

Send Report to PCP/Clinic:  CODE:


Address/Telephone Number:

Original ACN (For Lab Use Only):

Specimen taken by:

# BABY TOO OLD FOR TESTING LETTER

## ORIGINAL

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OREGON STATE PUBLIC HEALTH LABORATORY  
John A. Kitzhaber, MD, Governor  
<<DATES>>

**Oregon Health Authority**  
P.O. Box 275  
Portland, OR 97207-0275  
Desk: 503-693-4174  
Fax: 503-693-5601  
TTY: 971-673-0372

RE: <<l1name>>, <<l1fname>>  
BIRTH DATE: <<birthd>>  
SPECIMEN DATE: <<curdtcoll>>  
LAB NUMBER: <<curlabno>>  
STATE: <<stateprogA>>

**NEWBORN SCREENING FOLLOW UP: BABY TOO OLD FOR TESTING**  
The Northwest Regional Newborn Screening Laboratory's testing is designed for newborns, which have been defined as "zero to six months of age". Our standards and cutoffs are tailored to this age group and are not applicable to older infants and children. We highly recommend proceeding directly to definitive testing if there are signs or symptoms of a metabolic disorder present in the child.


Listed below is a metabolic laboratory we would recommend to provide Tandem Mass Spectrometry (MSMS) testing on older children. Also listed, are recommendations for further diagnostic testing for the other disorders on the newborn screening battery\*.

**MSMS Testing (AKA Expanded or Supplemental Newborn Screening)** this includes testing for selected amino acid, fatty acid, organic acid and urea cycle disorders:  
Baylor University Medical Center at Dallas  
3812 Elm Street  
Dallas, Texas 75226  
Telephone: 214-820-4533  
[www.baylorhealth.edu/fnd](http://www.baylorhealth.edu/fnd)

<b>Biotinidase Deficiency:</b> Biotinidase enzyme assay	<b>Galactosemia:</b> Galactose-1-Phosphate Galactose-1-PUT
<b>Pediatric Biochemical Genetics</b> 655 West Baltimore St Rm 7-042 Baltimore, Maryland 21201 Telephone: 410-706-2810	<b>University Children's Genetic Lab</b> 116 East Broadway Glendale, CA 91205 Telephone: (818) 548-0999 FAX: (818) 548-1555
<b>Congenital Hypothyroidism:</b> Serum - Free T4, TSH Done at most local laboratories	<b>Congenital Adrenal Hyperplasia:</b> Serum - 17-OH-Progesterone Done at most local laboratories
<b>Sickle Cell Disease:</b> Isoelectric Focusing/High Performance Liquid Chromatography Done at most local laboratories	

\*These laboratories are listed for your convenience only. You may send your specimen to any accredited laboratory that provides the appropriate testing.

## UPDATED

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<<DATES>>

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P.O. Box 275  
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Desk: 503-693-4174  
Fax: 503-693-5601  
TTY: 971-673-0372


RE: <<l1name>>, <<l1fname>>  
BIRTH DATE: <<birthd>>  
SPECIMEN DATE: <<curdtcoll>>  
LAB NUMBER: <<curlabno>>  
STATE: <<stateprogA>>

**NEWBORN SCREENING FOLLOW UP: BABY TOO OLD FOR TESTING**

- The Northwest Regional Newborn Screening Laboratory's testing is designed for newborns which have been defined as "zero to six months of age".
- Our standards and cutoffs are tailored to this age group and are not applicable to older infants and children.
- Please consult with a specialist if you are concerned about this baby's development
- Contact the Newborn Screening Coordinator for more information if needed.

# ABNORMAL FOLLOW UP: FALSE POSITIVE CLOSURE LETTER

## ORIGINAL

 PUBLIC HEALTH DIVISION  
Oregon State Public Health Laboratory - Newborn Screening  
John A. Kitzhaber, MD, Governor

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TTY: 971-673-0372

August 19, 2013

Dr. Provider  
1234 Street  
Portland OR 97222  
Telephone: 503-111-2222  
FAX: 503-111-2223

RE: **baby**  
Birth date: 8/1/13  
Specimen dates: 8/3/13  
Abnormal results:  
**C3DC=0.52, µM/L (normal<0.4 µM/L)**  
Plasma Acylcarnitines: **see attached**  
Urine Organic acids: **see attached**

Dear Dr,

This is to follow up regarding this infant. The first newborn screening result showed abnormal acylcarnitines which was suggestive of malonic aciduria or a false positive. Confirmatory testing does not support the diagnosis of malonic aciduria. Therefore, we regard this as a false positive requiring no further testing or treatment.


Thank you for your continued support of newborn screening. We are happy to provide assistance to you, as you need. Please contact the on-call newborn screening metabolic medical consultant or me, if you have further questions at 503-494-7859, or if after hours or urgent through the paging operator here at OHSU: 503-494-9000.

Name \_\_\_\_\_ MD  
Metabolic Medical Consultant to  
Oregon State Public Health Laboratory  
Telephone:  
FAX:  
Pager:  
Email:

Michael R. Skeels, PhD, MPH  
Director  
Oregon State Public Health Laboratory

Attachment:  
1. Plasma Acylcarnitines  
2. Urine Organic Acids

## UPDATED

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John A. Kitzhaber, MD, Governor

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P.O. Box 275  
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Desk: 503-693-4174  
Fax: 503-693-5601  
TTY: 971-673-0372


September 10, 2014

Dr. Provider  
1234 Street  
Portland OR 97222  
Phone: 503-111-2222  
Fax: 503-111-2223

RE: **baby**  
Birth date: 8/1/13

Confirmatory Tests  
Plasma Acylcarnitines: **see attached**  
Urine Organic acids: **see attached**

**NEWBORN SCREENING FOLLOW UP**

**CASE STATUS: CLOSED AS FALSE POSITIVE** 

Confirmatory testing does not support the diagnosis of Malonic Aciduria.

For questions please contact the Newborn Screening program or one of the Metabolic Medical Consultants below.


Dr. \_\_\_\_\_  
Metabolic Medical Consultants to  
Oregon State Public Health Laboratory  
Phone  
FAX  
After hours/Urgent Pager  
Email

Michael R. Skeels, PhD, MPH  
Director  
Oregon State Public Health Laboratory

Attachment:  
1. Plasma Acylcarnitines  
2. Urine Organic Acids

# ABNORMAL FOLLOW-UP: CONFIRMED POSITIVE CLOSURE LETTER

## ORIGINAL

 PUBLIC HEALTH DIVISION  
Oregon State Public Health Laboratory - Newborn Screening  
John A. Kitzhaber, MD, Governor  
August 5, 2013

**Oregon Health Authority**  
P.O. Box 275  
Portland, OR 97207-0275  
Desk: 503-693-4174  
Fax: 503-693-5601  
TTY: 971-673-0372

RE: **baby**  
Birth date: 7/11/13  
Specimen dates: 7/12/13, 7/26/13  
Abnormal results:  
▪ Methionine = 59 µM/L (normal <100)  
▪ Methionine = 304 µM/L (normal <100)  
Confirmatory studies date & results: 7/13/13  
Plasma Amino Acids – see attached information

Provider  
Address  
City State Zip  
Telephone:  
FAX:

Dear Provider,

This is to follow up regarding this newborn. Newborn screening results showed an abnormal amino acid, specifically, methionine. Confirmatory studies reveal abnormal quantitative plasma amino acids, specifically an elevated methionine. These results are consistent with Homocystinuria.

We would strongly recommend baby and his family be referred to a metabolic specialist for evaluation, treatment and counseling regarding the implications of these results. Please see the attached information for a list of metabolic specialists and clinics that are available to take referrals in New Mexico.

We are happy to provide assistance to you, as you need. Please contact the on-call newborn screening metabolic medical consultant or me, if you have further questions at 503-494-7859, or if after hours or urgent through the paging operator here at OHSU.


Dr. \_\_\_\_\_  
Metabolic Medical Consultant to  
Oregon State Public Health Laboratory  
Telephone:  
Pager:  
Email:

Michael R. Skeels, PhD, MPH  
Director  
Oregon State Public Health Laboratory

Attachments:  
1. Plasma Amino Acids  
2. Referral Information  
3. Fact Sheet - Homocystinuria

CC: NBSP

## UPDATED

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Fax: 503-693-5601  
TTY: 971-673-0372

April 28, 2014

Dr. \_\_\_\_\_  
Address  
City State Zip  
Telephone:  
FAX:

RE: **baby**  
Birth date: 4/16/14  
Confirmatory studies date & results: 4/23/14  
▪ Amino Acid/Plasma – PHE=1648

**NEWBORN SCREENING FOLLOW UP  
CASE STATUS: POSITIVE PKU**

Treatment should be started immediately. This infant and the family should be referred to metabolic specialists for evaluation, treatment and counseling regarding the implications of these results. Thank you for your support in newborn screening.

We are happy to provide assistance to you, as you need. Please contact the on-call newborn screening metabolic medical consultant or me, if you have further questions at 503-494-7859, or if after hours or urgent through the paging operator here at OHSU: 503-494-9000.

\_\_\_\_\_, MD  
Metabolic Medical Consultant to  
Oregon State Public Health Laboratory  
Telephone:  
FAX:  
Pager:  
Email:

Michael R. Skeels, PhD, MPH  
Director  
Oregon State Public Health Laboratory

Attachments:  
1. Referral listings



# FOLLOW-UP LETTERS AND ACTIONS

**Fax numbers for the PCP were added to the letter formats**

**Faxing PCP instead of snail mail has reduced turnaround time for**

- **serum results**
- **requested repeats to be submitted**
- **information regarding PCP changes**



# SYSTEM UPDATES

## Faxing results from the database

MSDS On-Line Search Results

Specimen #: \_\_\_\_\_ Patient Number: \_\_\_\_\_ Form No: \_\_\_\_\_ Patient: \_\_\_\_\_

Demographics: Released Spec Type: First Date Collected: 02/06/2014  
 Mailed - Date Reported: 02/14/2014 Notebook Status: [Icon]


Group	Disorder	Mnemonic	Result	Status	Release Date	Reference Range
CH	CH	NOR	Normal	Normal	02/12/2014	5 - 35 µg/dL, TS...
CAH	CAH	NOR	Normal	Normal	02/12/2014	<= 120 ng/mL
CF	CF	EL	Elevated	Abnormal	02/14/2014	<= 90.00 ng...
HGB	HGB	NOR	Abn Hb not found	Normal	02/13/2014	Normal = FA
BIO	BIO	NOR	Normal	Normal	02/13/2014	Normal Has Color
GAL	GAL	NOR	Normal	Normal	02/12/2014	>= 3.50 U/mL
AAM	Agg	NOR	Normal	Normal	02/12/2014	Agg <= 110 µM
AAM	OT/ASA	NOR	Normal	Normal	02/12/2014	CkC <= 70 µM
AAM	MSUD	NOR	Normal	Normal	02/12/2014	Leu <= 270 µM
AAM	Hom	NOR	Normal	Normal	02/12/2014	Met <= 80 µM
AAM	PKU	NOR	Normal	Normal	02/12/2014	Phe <= 180 µM
AAM	TYR	NOR	Normal	Normal	02/12/2014	Tyr <= 480 µM...
FAO	SCAD/...	NOR	Normal	Normal	02/12/2014	C4 <= 1.40 µM
FAO	MCAD	NOR	Normal	Normal	02/12/2014	C8 <= 0.70 µM
FAO	LCHAD	NOR	Normal	Normal	02/12/2014	C16OH <= 0.10...
FAO	VLCAD	NOR	Normal	Normal	02/12/2014	C14:1 <= 0.60 µM
FAO	CPT1	NOR	Normal	Normal	02/12/2014	<= 50.00
FAO	CPT2	NOR	Normal	Normal	02/12/2014	C16 <= 8.0 µM
FAO	CIUD	NOR	Normal	Normal	02/12/2014	CO >> 7.0 µM
QA	PAM/...	NOR	Normal	Normal	02/12/2014	C3 <= 7.5 µM
QA	MA	NOR	Normal	Normal	02/12/2014	C3OC <= 0.25 µM
QA	IVA/2/...	NOR	Normal	Normal	02/12/2014	C5 <= 0.60 µM
QA	BKT	NOR	Normal	Normal	02/12/2014	C5T <= 0.10 µM
QA	3MCC/...	NOR	Normal	Normal	02/12/2014	C5OH <= 0.90...
QA	GA1	NOR	Normal	Normal	02/12/2014	C5OC <= 0.90 µM
QA	MADD...	NOR	Normal	Normal	02/12/2014	C16:1 <= 80 µM

Comment: Repeat bloodspot specimen requested

Test Name Avg Seq Mnemonic Value Status Date Reference Range  
 T4 19.93 1 NOR 19.93 Normal 02/12/2014 5 - 35 µg/dL, TSH age adjusted

Sample Information  
 Name [L, F] \_\_\_\_\_ Sex Female Infection Date @ Time \_\_\_\_\_ Age At Collection 1 day(s)  
 Birth Weight 2278 gms Mother's Name \_\_\_\_\_ Transit Time 4 day(s)  
 Birth Date @ Time \_\_\_\_\_ K&A Part 1 \_\_\_\_\_ Gest. Age Wks \_\_\_\_\_  
 Transfused No \_\_\_\_\_ Submitter: \_\_\_\_\_

Actions: Mailers, Fax Mfr, Report, To CMS, CMS OLS, Old Report, E-Mail, To HL7



# SYSTEM UPDATES

Created diagnosis codes for all conditions screened for

Can now pull reports based off a diagnosis code

Prior to this the only tracking of confirmed cases was handwritten notes and excel spreadsheets

The screenshot shows the 'CMS-III Search' application window. The 'Disorders' list on the left includes codes such as CH-91001, CAH-91002, and S1003. The 'Final Diagnosis' table is as follows:

Diag Code	Description
<input checked="" type="checkbox"/> 1	CYSTIC FIBROSIS
<input type="checkbox"/> 2	CF CARRIER
<input type="checkbox"/> 3	CFTR Related Metabolic syndrome
<input type="checkbox"/> 4	CF not detected by NBS

A red arrow points to the 'Diagnosis' icon in the left-hand navigation pane. Below the main window, a 'Diagnoses Assigned' table is visible:

Type	Disorder	Diagnosis	Ray No.	Diag Date	User	Notify Date	Resp Code
F	CF	1 - CYSTIC FIBROSIS		03/12/2014	Sara Derenstam	03/12/2014	S1003

# IMAGE RETRIEVAL



CMR-III Search

Specimen # [redacted] Patient # [redacted] Form No. Patient [redacted] Mother: [redacted]  
Case Status: Closed Spec Type: Repeat  
Date Reported: 09/29/2014

Notes Act-Closed(5)  
Act-Pending(0) Physician(0)

Printed on: 10/17/2014 10:50 PDT

MRN: 190306

TSH: 2.350 mIU/mL  
Date / Time: 14 October 2014 11:28 PDT

TSH: 2.350 mIU/mL  
Normal Low: 0.600 Normal High: 10.000

Contributor System: PowerChart

Accession Number: 000082014287000139

Status: Auth (Verified)

Source Type: Blood

Source:

Collected on 14 October 2014 11:28 PDT

Action List:

Order by R on 14 October 2014 11:27 PDT  
Action status: Completed

Perform by Biggs, Leota on 14 October 2014 12:39 PDT  
Action status: Completed

Description	Date	ID
20142680997.pdf	10/17/2014	0

Left-hand menu: Daily Work, Case Information, Call Log, Disorders, Image Retrieval, Referrals, Audit Trail, Test Referrals

Right-hand toolbar: OK, Cancel, Retry, Scanner, Add Image, Delete Image, Print, Mail, Fax, Mailer, Hear Demog, Merge

# HOSPITAL RECORDS ACCESS



The screenshot shows a web browser window with the URL [https://connect.ohsu.edu/Epiclink/common/epic\\_login.asp](https://connect.ohsu.edu/Epiclink/common/epic_login.asp). The page header features the Oregon Health & Science University logo and the tagline "Where Healing, Teaching & Discovery Come Together".

The main content area is divided into several sections:

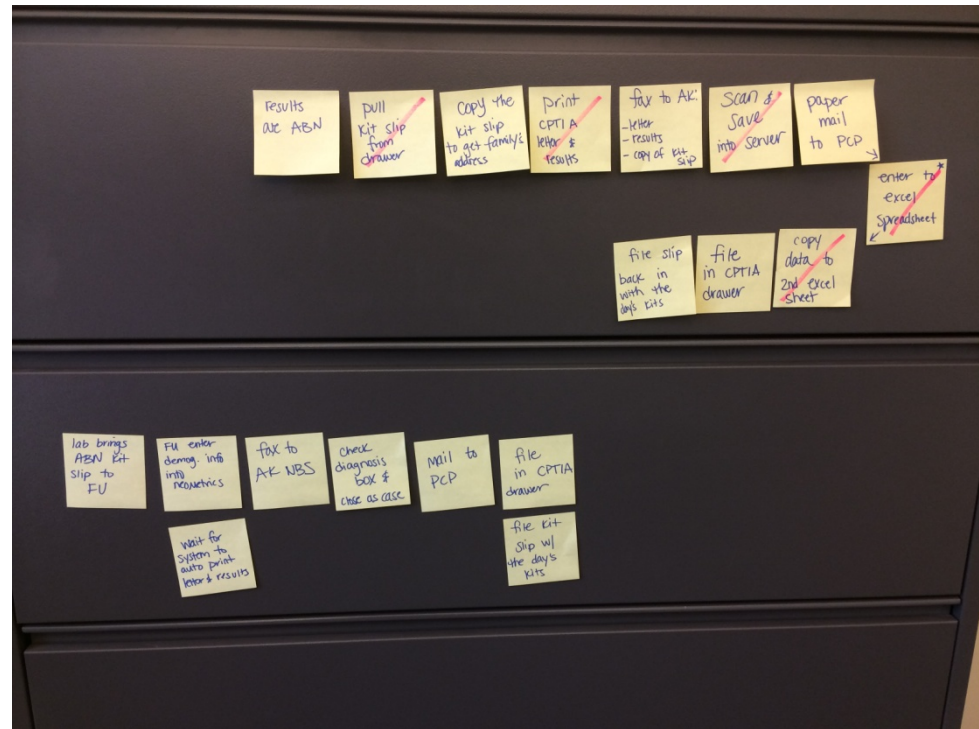
- OHSU Connect**: A banner featuring two doctors in white coats. Text reads: "Stay connected to your patient's care at OHSU. If you refer patients to OHSU or OHSU Doernbecher Children's Hospital, you can now track your patient's care in real time with OHSU Connect."
- OHSU Connect Log In**: A login form with fields for "Username" and "Password", a "Sign In" button, and links for "Password Management" and "Personalize or Reset Password".
- Why use OHSU Connect?**: A section explaining the benefits of the system, such as real-time access to medical records and direct communication with providers.
- Contact Information**: A section providing technical assistance details, including phone numbers (503-494-4567 or 800-245-6478) and an email address (laison@ohsu.edu).
- Account Services & Info**: A sidebar with links for "Sign Up Today", "Physician Resources", "System Requirements", "Terms & Conditions", "Notice of Privacy Practices", and "Deactivate Your Account".

At the bottom of the page, there is a small copyright notice: "EpicCare Link™ licensed from Epic Systems Corporation. Copyright © 1997-2012. All Rights Reserved. U.S. Patents 5,701,091 and 5,301,105. Other U.S. Patents pending."

# CHANGES IN WORKFLOW

## SPECIAL POPULATION CPT1A-ARCTIC VARIANT

**Average of 11 steps in workflow process cut down to 6**



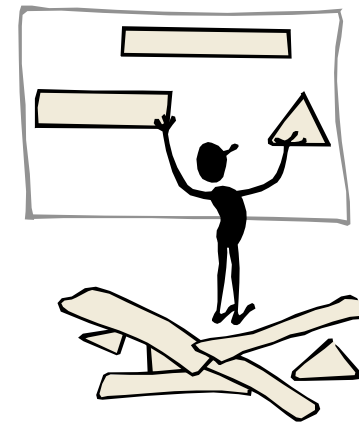
# FUTURE PLANS

- **Complete updating the Practitioner's manual with our Nurse Educator (no longer printed and is only available online)**
- **Update Fact sheets including separate provider and parent versions**
- **Revise the bloodspot collection kit**
- **Complete SCID follow up materials**
  
- **Document follow up activities into flowcharts similar to the format the lab has for our algorithms-these are now part of CAP inspections**

# IN SUMMARY



1. **Think outside the box**
2. **Don't be afraid to ask why something is being done a certain way**
3. **Accept change and know it is inevitable**
4. **Time is always needed**



# CONTACT

**Sara Denniston, BS**

**NBS Follow-Up Coordinator**

**Oregon State Public Health Lab**

**503-693-4173**

**[sara.denniston@state.or.us](mailto:sara.denniston@state.or.us)**