EVALUATING AND IMPLEMENTING CHANGE IN FOLLOW-UP

SARA DENNISTON, BS
OREGON STATE PUBLIC HEALTH LAB
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
QNS/ INSUFFICIENT BLOOD NOTIFICATION

ORIGIONAL

PUBLIC HEALTH DIVISION
OREGON STATE PUBLIC HEALTH LABORATORY

URGENT FOLLOW UP REQUESTED

July 3, 2014

Fax: 

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 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 DeRoulston, BS
Newborn Screening Follow-Up Coordinator

UPDATED

PUBLIC HEALTH DIVISION
OREGON STATE PUBLIC HEALTH LABORATORY - Newborn Screening

NEWBORN SCREENING URGENT FOLLOW UP REQUESTED

June 9, 2014

Fax: 503-

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 DeRoulston, BS
Newborn Screening Follow-Up Coordinator
BABY TOO OLD FOR TESTING LETTER

ORIGINAL

[Image of a letter from Oregon Health Authority, which includes sections on newborn screening follow-up, indicating that babies are too old for testing due to their age.]

UPDATED

[Image of an updated letter from Oregon Health Authority, with additional information on newborn screening follow-up, including a list of conditions not tested for in older babies, and contact information for further testing.]
ABNORMAL FOLLOW UP: FALSE POSITIVE CLOSURE LETTER

**ORIGINAL**

August 19, 2013

Dr. [Name]
1234 Street
Portland OR 97222

RE: Baby
Birth date: 8/1/13
Specimen date: 8/3/13
Algal results: 0.35 µM, normal is <0.4 µM
Urine Organic acids: see attached

Dear Dr.,

This is to follow up regarding the infant. The first newborn screening result showed abnormal acylcarnitines which was suggestive of maleic aciduria or a false positive. Confirmatory testing does not support the diagnosis of maleic 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 newborn screening metabolic medical consultant at the Oregon State Public Health Laboratory by phone: 903-404-9395 or by fax at 903-404-9900.

Name: [Name]
Metabolic Medical Consultant to: Oregon State Public Health Laboratory
Phone: 903-404-9395
Fax: 903-404-9900
Email: [Email]

Attachment:
1. Plasma Acylcarnitines
2. Urine Organic Acids

**UPDATED**

September 16, 2014

Dr. [Name]
1234 Street
Portland OR 97222

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 Maleic Aciduria.

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

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

Attachment:
1. Plasma Acylcarnitines
2. Urine Organic Acids
ABNORMAL FOLLOW-UP: CONFIRMED

POSITIVE CLOSURE LETTER

ORIGINAL

Dear Provider,

This is to follow up regarding the newborn, [name], whose screening results showed an abnormal amino acid, specifically, methionine. Confirmatory studies revealed abnormal quantitative plasma amino acids, specifically an elevated methionine. These results are consistent with [condition].

We would strongly recommend that the 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 [phone number] or [email] through the paging operator by 0100.

Dr.
Metabolic Medical Consultant
to Oregon State Public Health Laboratory
Telephone:

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

ATTACHMENTS:
1. Plasma Amino Acids
2. Referral Information
3. Pedi Service - [condition]

UPDATED

Dr.

April 28, 2014

Re: baby
Birth date: 4/16/14
City State Zip
Telephone:
Fax:

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 [phone number] or [email] through the paging operator here at [phone number].

[Signature]

Michael R. Skoerts, PhD, MPH
Director
Metabolic Medical Consultant
to Oregon State Public Health Laboratory

ATTACHMENTS:
1. Referral Information
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
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
IMAGE RETRIEVAL

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, Lecta on 14 October 2014 12:39 PDT
Action status: Completed
HOSPITAL RECORDS ACCESS
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

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