



Newborn screening follow-up for metabolic disorders during the COVID-19 pandemic:

Experiences from the Oregon Metabolic
Clinic

June 17, 2020

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Our Speakers for today



The team from Oregon Health & Science University



Sarah Viall

MSN, PNP
Nurse Practitioner



Leah Wessenberg

MN, FNP
Nurse Practitioner



Joyanna Hansen

Ph.D., R.D., L.D
Metabolic Dietitian

Disclosures



- ❑ Speakers received an honorarium provided by Nutricia for this presentation.
- ❑ Sarah has no other conflicts of interest to disclose.
- ❑ Joyanna has no other conflicts of interest to disclose.
- ❑ Leah has received honoraria from BioMarin pharmaceuticals for participation on their Advisory Board.
- ❑ None of above pose any conflict of interest for this presentation.

Learning Objectives



- Recognize the challenges of newborn screening (NBS) follow-up during a pandemic.
- Discuss alternative ways of working with new families identified through newborn screening.
- Recognize the potential for improved patient care opportunities in a post-Covid-19 world.

NBS in the time of COVID-19...

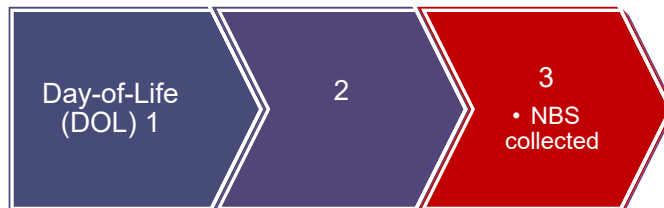
All patient information has been de-identified on all slides.

Case 1: Rose



Day-of-Life
(DOL) 1

Case 1: Rose



Case 1: Rose

This baby's newborn screen has **Critical** value(s):
Critical: Leucine = 573.4
Results concerning for Maple Syrup Urine Disease.



Case 1: Rose



Case 1: Rose

Lab View		03/ /20 14:33 EDT
<input type="checkbox"/>	Valine Level	
<input type="checkbox"/>	Valine Level, Plasma	H 1,077
<input type="checkbox"/>	Cystine, Plasma	76
<input type="checkbox"/>	Methionine Level, Plasma	17
<input type="checkbox"/>	Cystathionine, Plasma	* H 206
<input type="checkbox"/>	Isoleucine Level	
<input type="checkbox"/>	Isoleucine Level, Plasma	H 632
<input type="checkbox"/>	Leucine	
<input type="checkbox"/>	Leucine, Plasma	H 3,167
<input type="checkbox"/>	Tyrosine, Plasma	60



Case 1: Rose

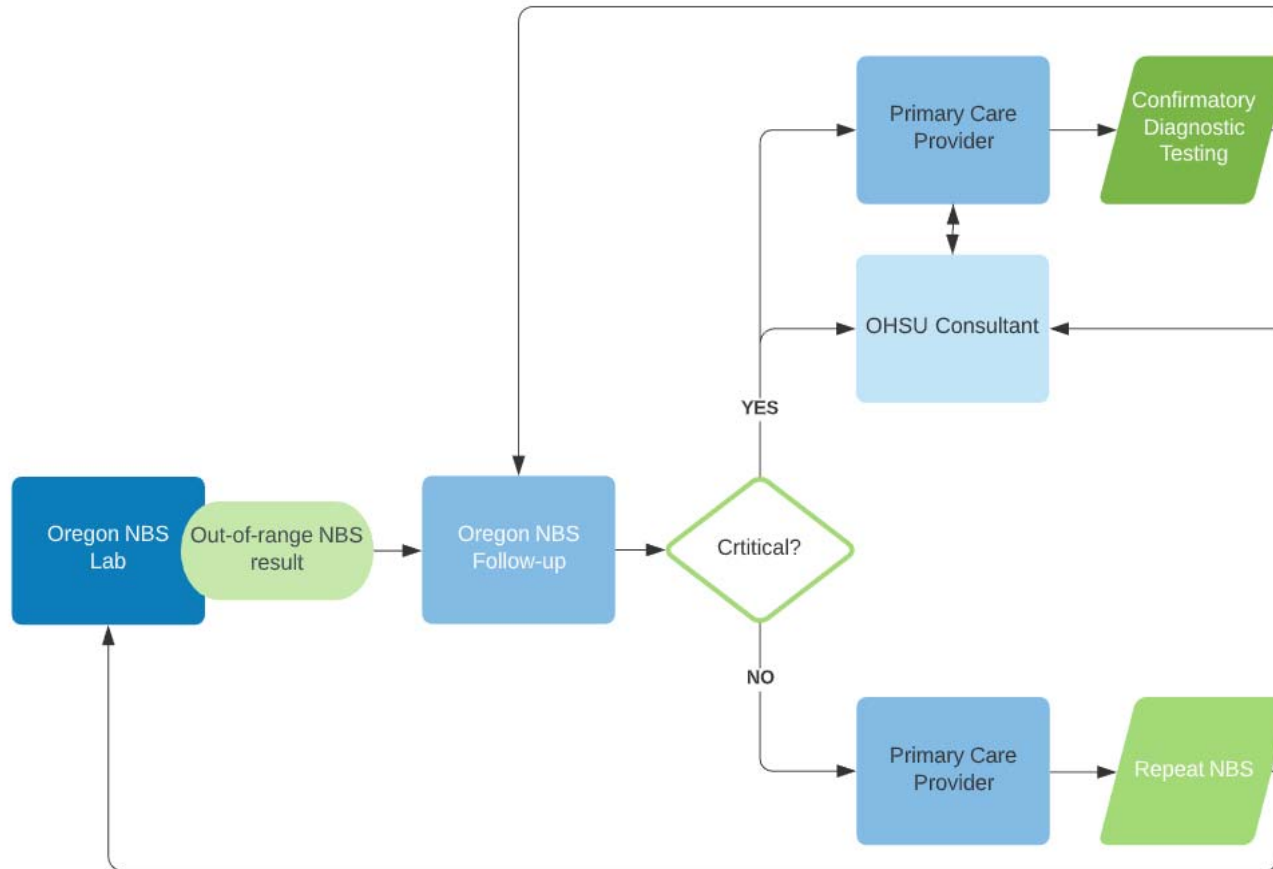


DOL 91: remains in the NICU, awaiting transplant

The Oregon Experience



Oregon Newborn Screening Follow-up

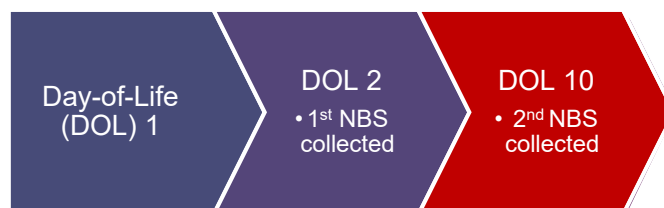


Case 2: Jack

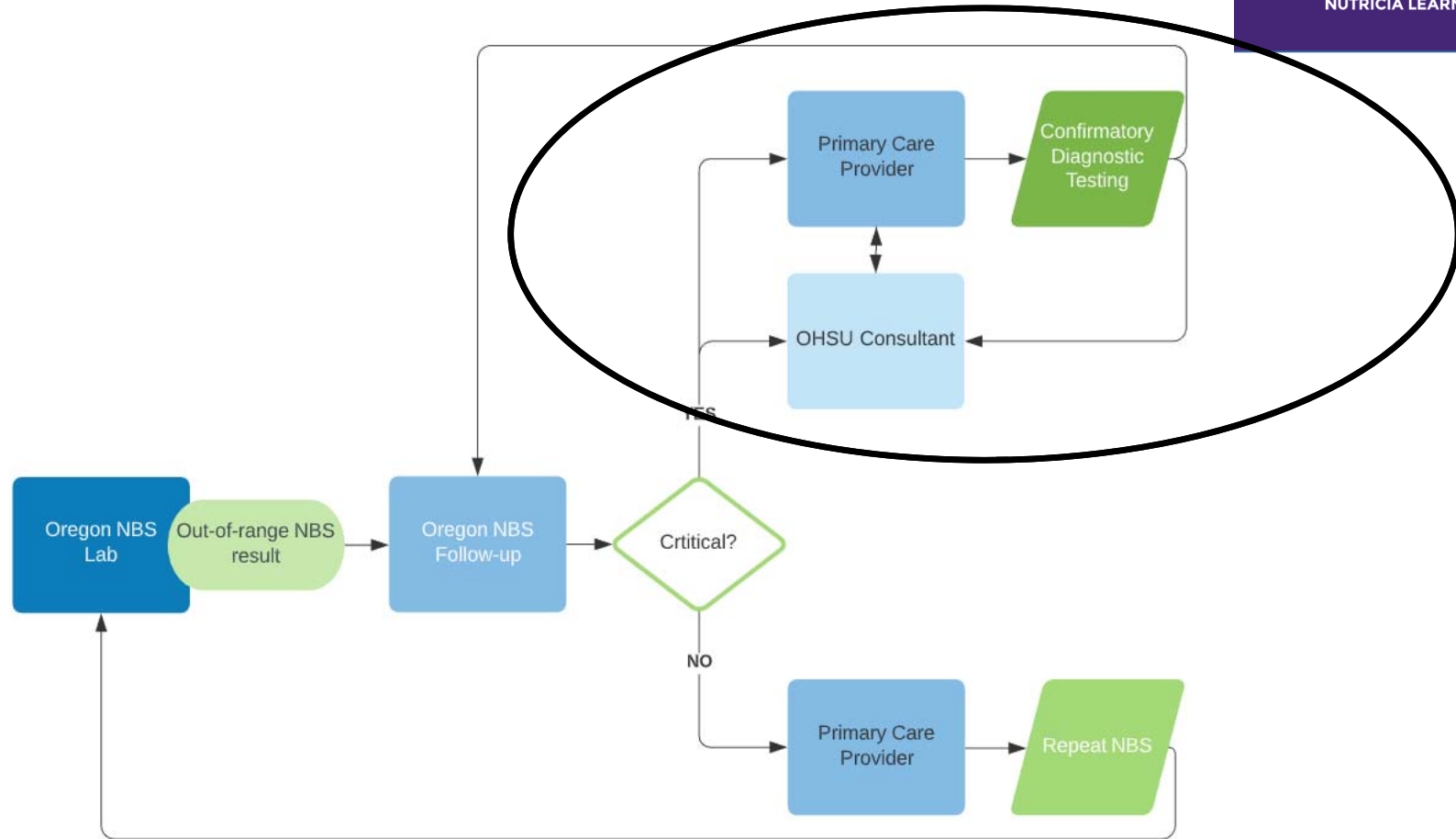


Day-of-Life
(DOL) 1

Case 2: Jack



Oregon Newborn Screening Follow-up

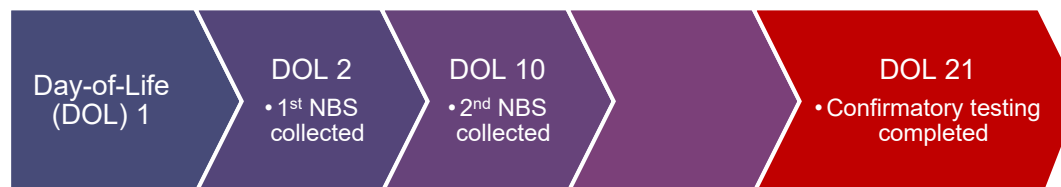


Case 2: Jack

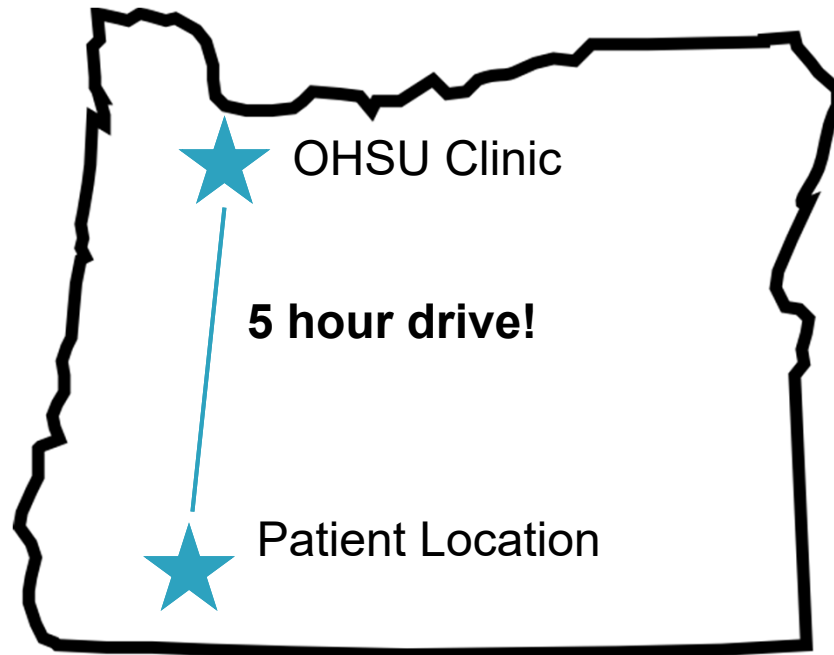
Confirmatory acylcarnitine profile, DOL 21:

- C16-OH: 0.53 (<0.31)
- C18:1-OH: 0.41 (<0.05)

Results consistent with LCHAD/TFP deficiency



Oregon: “Stay Home, Save Lives”

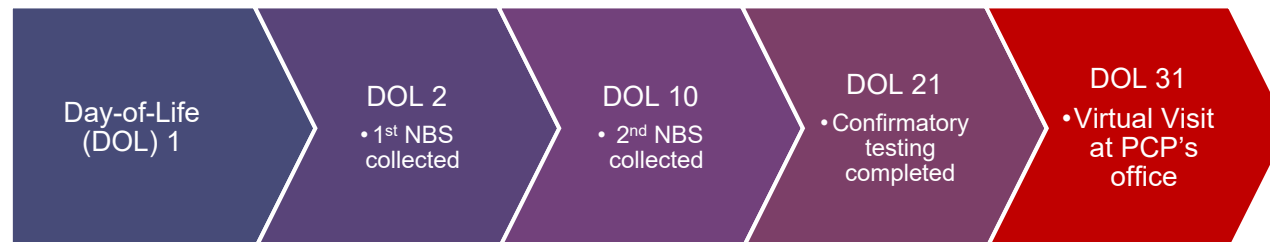


Other considerations:

- Interpreter needed
- Primary Care Provider (PCP) attempted Virtual Visit, unsuccessful with this patient

Case 2: Jack

Virtual Visit between patient & OHSU
Medical Genetics team at PCP's office



NBS Challenges

Typical

- ❑ Correct contact information
- ❑ Care coordination
- ❑ Language barriers
- ❑ Identifying specialists
- ❑ Conveying urgency
- ❑ “PKU Test”
- ❑ Financial stressors

COVID-Era

- ❑ Delayed well-child care
- ❑ Conveying safety of medical setting
- ❑ Provider communication and coordination
- ❑ Office closures
- ❑ Outpatient management of conditions
- ❑ Utilization of telemedicine
- ❑ Medical formula and medication
- ❑ Follow-up

Typical Challenges In An Atypical Time

Correct contact information

- ❑ Limits of alternative numbers (i.e. other family members, caregiver's work)
- ❑ Home situation changes due to employment or child care
- ❑ Facilities closing or operating alternative hours

- Consider leveraging PCPs and public health systems (i.e. immunization databases)

Typical Challenges In An Atypical Time



Care coordination

- ❑ Entire systems developing new protocols and means of care delivery without preparation
- ❑ Lay-offs and hiring freezes reducing available staff
- ❑ Use external resources and peer experiences via the National Coordinating Center (NCC) Regional Genetics Networks

➤ Western States Regional Genetics Collaborative Telehealth Resources

Typical Challenges In An Atypical Time

Language barriers

- ❑ Limited or reduced access to interpreter services
 - ❑ Difficulty incorporating interpreters on telemedicine platforms
 - ❑ Explaining use of technology
 - ❑ Providing culturally-sensitive care across technology
-
- [CMS Practical Guide on Building an Organizational Response to Health Disparities](#)
 - [CLAS Guidelines in Mobile Health](#)

Typical Challenges In An Atypical Time

Identifying specialists

- ❑ Finding the right specialist, scheduler, and location
- ❑ Availability of telemedicine

- [ACMG Find a Genetic Clinic](#)
- [Genetics Home Reference: How can I find a genetics professional in my area?](#)
- [Telemedicine & Telehealth Service Provider Directory](#)

Typical Challenges In An Atypical Time

Conveying urgency

- ❑ Allow for reasonable flexibility with non-urgent follow-up
- ❑ Work with health department partners
- Direct PCPs to [AAPs Preparedness for Pediatric Practices, NBS in Emergencies](#)

“PKU Test” and other misconceptions

- [NCC Resource Repository](#)
- [HRSA NBS Communication Guide](#)

Typical Challenges In An Atypical Time



WELL-BEING DECEMBER 9, 2019

More Americans Delaying Medical Treatment Due to Cost

BY LYDIA SAAD

Source: Gallup

THE CORONAVIRUS CRISIS

It's Official: U.S. Economy Is In A Recession

June 8, 2020 · 1:30 PM ET

Source: NPR

Financial stressors

- ❑ Loss of employment or income
- ❑ Loss of insurance
- Reasonable flexibility for those requesting delay in medical, transportation and other expenses

COVID-Era Challenges: Specimen Collection



Delayed well-child care

- Including second specimens or repeats of unsatisfactory screens and well-baby, follow up exams
 - Separate clinic space for well-children
 - Offering different clinic hours for well-children
 - Communicate time-sensitivity, urgency of newborn screening
 - Newborn Screening may not feel like necessary care during a time when only “urgent” services available.
- [AAP Guidance on Pediatric Well Care during COVID-19](#)
- [AAP Guidance on Newborn Screening During COVID-19](#)

COVID-Era Challenges: Results Review

Provider communication and coordination

- ❑ Best contact information
 - ❑ Getting in touch with “a human” and not just a phone tree
 - ❑ Fewer office staff available to answer phones
- ❑ Many working from home
 - ❑ Direct contact difficult
 - ❑ Lack of access to direct line, secure fax or scanning

Office closures

- ❑ Not set up with on-call coverage
- Oregon model: state NBS team helps establish communication with a follow up provider

COVID-Era Challenges: Diagnosis To Management



Outpatient management of conditions

- ❑ Safety of discharging new and complex diagnoses
 - Evaluation/stabilization in emergency dept with urgent labs
 - Is a hospitalization needed?
 - Social/economic barriers
 - Access to care locally
 - COVID-19 risk factors

COVID-Era Challenges: Diagnosis To Management



Utilization of telemedicine

- ❑ Care in partnership with PCP
 - ❑ Reliance on local resources such as labs, interpreters, nurses
 - ❑ Revolution in changes to payment and service reimbursement
 - ❑ Non-Licensed Independent Provider (LIP) scheduling and billing challenges
 - ❑ Out of State licensure
-
- [Western States Regional Genetics Collaborative Telehealth Resources](#)
 - [COVID-19 state-related actions](#)

COVID-Era challenges: Treatment and follow up



Medical formula and medications

- ☐ Shipping samples directly from manufacturer
- ☐ Mailing samples in clinic to patient
- ☐ Mail-order pharmacies

Follow up

- ☐ Keeping contact info current
- ☐ Plan for in-person versus virtual visits: a protocol?
- ☐ Faxing lab orders to local labs

Envisioning A Post-COVID Future..



- ❑ Opportunity to reimagine clinical practice model & collect outcome data on the impact of telemedicine
- ❑ Improved technological capacity and skills
- ❑ Movement towards telehealth payment parity

Envisioning A Post-COVID Future..



- ❑ Meeting patients where they are, particularly rural or differently-abled
- ❑ Availability of more frequent and convenient follow-up
- ❑ Opportunities for improved communication and cooperation with PCPs/pediatricians

Resources



- National Coordinating Center for the Regional Genetics Networks: <https://nccrcg.org/>
 - Resource Repository:
<https://airtable.com/shrLdFiGZcKyq214G/tblQBH1DXgpEILn8Q?backgroundColor=yellow&viewControls=on>
- Western States Regional Genetics Collaborative Telehealth Resources:
<http://www.westernstatesgenetics.org/telehealth-resources/>
- CMS “A Practical Guide to Implementing the National CLAS Standards”:
<https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/CLAS-Toolkit-12-7-16.pdf>
- Tirado, M. Perspect Health Inf Manag. 2011:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3035829/>
- ACMG “Find a Genetic Clinic”: <https://clinics.acmg.net/>
- Genetics Home Reference “How do I find a genetics professional in my area?”
<https://ghr.nlm.nih.gov/primer/consult/findingprofessional#:~:text=To%20find%20a%20genetics%20professional,who%20participates%20in%20your%20plan.>

Resources

- The University of Arizona, Telemedicine & Telehealth Service Provider Directory:
<https://telemedicine.arizona.edu/servicedirectory>
- American Academy of Pediatrics
 - “Preparedness for Pediatric Practices, Newborn Screening in Emergencies” :
http://www.aap.org/en-us/Documents/disasters_newborn_screening_handout.pdf
 - “Guidance on Providing Pediatric Well-Care During COVID-19”:
<https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/guidance-on-newborn-screening-during-covid-19/>
 - “Guidance on Newborn Screening During COVID-19”:
<https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/guidance-on-newborn-screening-during-covid-19/>

Resources



- HRSA, Secretary's Advisory Committee on Heritable Disorders in Newborns and Children: <https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/Resources/achdnc-communication-guide-newborn.pdf>
- Hilgart, JS et al. Genet Med. 2012: <https://www.nature.com/articles/gim201240.pdf>
- Center for Connected Health Policy; Covid-19 Related State Actions: <https://www.cchpca.org/resources/covid-19-related-state-actions>

Thank you!
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