

Newborn Screening (NBS) Technical Advisory Committee (TAC)

Ornithine Transcarbamylase Deficiency (OTCD)

FAMILY PERSPECTIVE

William Tyler Raynz

November 2nd – 10th 2018 (8 Days)

Normal Pregnancy

Early Onset

Mother (Victoria) showed no symptoms entire life

High Ammonia levels not diagnosed until arriving at Seattle Children's (Day 4)



Other Shared Stories

- “Mainly effects Boys?”
- Treatment
- Improve health outcomes
- Quality of Life

Name	Article Date	Gender	Age	Status
Baine B.	2/15/2019	M	7	Deceased
Elliot P.	2/7/2019	M	14	Deceased
Trevor S.	1/22/2019	M	UNK	Alive
Luis	9/25/2018	M	5	Deceased
Montana L.	8/3/2018	F	6	Alive (T)
Kayden H.	7/20/2018	M	6	Alive
Tina H.	7/20/2018	F	19	Alive
Paula H.	7/20/2018	F	26	Alive
Wendy H.	5/7/2019	F	UNK	Alive
Zachary H.	5/7/2019	M	1	Deceased
Jenna H.	5/7/2019	F	UNK	Alive
Female H.	5/7/2019	F	UNK	Alive
Tori C.	4/29/2019	F	18	Alive
TJ C.	4/29/2019	M	UNK	Deceased
Mya B.	4/10/2019	F	11	Alive
Zoey Z.	12/19/2017	F	20	Deceased
Aiden S.	9/24/2020	M	9	Alive (T)
Kayde M.	2/13/2020	M	0	Deceased
Jack S.	1/7/2020	M	3	Alive (T)
August S.	4/12/2021	M	0	Deceased
Samson B.	8/7/2019	M	14	Deceased
Ava T.	8/18/2019	F	11	Alive (T)
Callan P.	10/4/2019	M	1	Alive (T)

PROTECTING FUTURE GENERATIONS

AWARENESS
&
PREPAREDNESS



June 16th, 2021

WHY WOULDN'T WE?

We have the Equipment

We know the Best Practice

We have the
Knowledge/Expertise/Staff



SURVIVORS



Questions?

Byron & Victoria Raynz (Parents) are always open to share their experience, perspective, and support for OTCD research, treatments, and anything else we can help with towards this cause. Please do not hesitate to contact us anytime if you feel there's any potential for being of assistance!

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