Good afternoon Mr. Chairman, members of the Committee, thank you for the opportunity to come before you today.

My name is Stephanie Walters. I work for the Department of Health and Welfare in the Division of Public Health-- Bureau of Clinical and Preventative Services. I am the Children and Youth with Special Health Care Needs Director and I oversee the Newborn Screening Program.

Why is NBS important?
I am here to share the importance of newborn screening. According to the Centers for Disease Control and Prevention or CDC, newborn screening is one of the nation's most successful public health programs, because when newborns receive an early diagnosis and treatment, families and health care providers can successfully manage many of the identified conditions, which improve the quality of life for the infant and significantly reduces the burden of health care costs. Newborn screening saves 5,000 lives annually in the United States, and between 20-30 lives in Idaho each year.

So, what exactly is newborn screening?
Newborn screening identifies conditions that can affect an infant's long-term health or survival. Early detection, diagnosis, and treatment can prevent death or disability and enable children to reach their full potential. There are three components of newborn screening in Idaho: hearing screening, critical congenital heart disease screening, and blood spot or metabolic screening. Before discharge from the hospital or birth center, infants receive a screen for hearing loss, are tested for critical congenital heart disease, and receive a blood spot test or metabolic screen where using a few drops of blood from the newborn's heel, the infant can be tested for certain genetic, endocrine, and metabolic disorders. Idaho requires the blood spot and the critical congenital heart disease screens. Parents have the right to refuse the blood spot screening for religious reasons. Hearing screening in Idaho is still voluntary with high screening rates.

I am here today to speak about the newborn screening related to the blood spot or metabolic screen. From this point forth when I say newborn screening, I will be referring to the blood spot screen. Newborn screening is the practice of testing every newborn for certain rare genetic and inherited conditions that could cause

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Senate Health & Welfare
January 26, 2022

developmental delays, slow growth, result in severe illness, brain damage, and possibly death. The conditions newborns are screened for differ in each state.

Idaho is a two-screen state, which means newborns are tested within 24-48 hours after birth, and then again at 10-15 days old. A sample of blood is obtained by pricking the infant's heel. The blood is then placed onto a special filter-paper collection card. These cards are then sent to a state-contracted laboratory and analyzed for 47 different conditions that could be detrimental and potentially life-threatening to the infant's health. While many disorders will be detected on the first screening, there are some conditions that are not detected until the infant is about two weeks old.

Newborn screening does not confirm an infant has a condition. If a positive screen is detected, parents will be notified immediately, and follow-up testing will be recommended by medical specialists here in Idaho.

Newborn Screening Program Mission

The mission of the Idaho Newborn Screening Program is to promote and protect the health of all Idaho newborns by early detection of potentially fatal and disabling conditions. We communicate with, support, and provide resources to families, physicians, medical specialists, and others to ensure that identified infants have access to timely and quality diagnostic testing and comprehensive treatment.

Newborn Screening Funding

Currently, funding for newborn screening is primarily generated via the fee associated with the purchase of newborn screening collection cards. The collection card fee pays for the testing of the specimen by the lab. Personnel and operating expenses related to the Idaho Newborn Screening Program come from federal funds associated with the Title V Maternal and Child Health Services Block Grant. There are no state general funds provided for newborn screening.

New Year, New Conditions

Idaho has been collecting blood spots since 1963. While each of the screened conditions is rare, collectively they affect about 1 in 1,000 infants. On average,

there are 20 to 30 infants diagnosed each year in Idaho. In 2020, a total of 21,534 infants received newborn screening and 24 infants were diagnosed with a newborn screening condition.

Laboratory technology allows screening for many conditions from a small amount of blood. As this technology evolves, new conditions can be added to Idaho's recommended panel of conditions that we screen for. The Newborn Screening Program relies on technical, clinical, and advisory groups to evaluate the addition of new conditions to our recommended screening panel. These deliberations are objective with opportunity for input from health care providers, medical experts, parents, advocates, legislators, and other public health programs. This decision is not as simple as adding the new condition to the screening test. It must take numerous matters into consideration including existing technology; accessible diagnostic testing and treatment; and that the cost of population-based screening for a specific condition outweighs the cost of risk-based screening or other approaches.

The Idaho Newborn Screening Program will expand the list of conditions for which it screens on February 1st, from 47 to a total of 51. The four new conditions are:

1. Glycogen storage disease type II (Pompe)
2. Mucopolysaccharidosis Type-1 (MPS-1)
3. Adrenoleukodystrophy (X-ALD)
4. Spinal Muscular Atrophy (SMA)

Glycogen storage disease type II (Pompe) and Mucopolysaccharidosis Type-1 (MPS-1) are both inherited lysosomal storage disorders that affect many different parts of the body. Lysosomes act as the recycling center of the cell. With Pompe and MPS-1, lysosomes cannot break down certain kinds of complex sugars and this causes undigested sugar molecules and other harmful substances to build up in cells of the body causing the varying symptoms found with these disorders.

Adrenoleukodystrophy (X-ALD) and Spinal Muscular Atrophy (SMA) are inherited disorders like Pompe and MPS-1. X-ALD occurs when very long chain fatty acids cannot be broken down in the body. These built up fats affect the nervous system and adrenal glands causing difficulties swallowing, weakness in the legs, seizures, weight loss, vomiting, and acute adrenal crisis, which is a life-threatening condition. SMA is caused by the loss of motor neurons of the spinal cord. Motor

neurons are specific nerve cells that control the muscles used for breathing and movement. Infants with SMA face many physical challenges, such as trouble with movement, breathing and swallowing. Early diagnosis and prompt treatment can make a significant impact on the length and quality of life of the infant.

Thank you for your time and attention. Mr. Chairman, members of the Committee, that concludes my presentation, and I will stand for questions.