CURE 4 THE KIDS FOUNDATION
Clinical Excellence.Compassionate Care.

March 20, 2025

The Honorable Fabian Donate, Chair
Senate Committee on Health and Human Services
Nevada State Legislature
401 S. Carson Street
Carson City, NV 89701

Submitted Electronically: senhhs@sen.state.nv.us

RE: Support for SB348 – Cost Savings and Public Health Benefits of Newborn Screening Modernization

Dear Chair Donate and Members of the Committee,

Early detection saves lives. Timely, comprehensive newborn screening is not just good healthcare policy—it is a critical public health investment that prevents suffering and significantly reduces long-term costs. On behalf of Cure 4 The Kids Foundation (C4K)—Nevada's only outpatient pediatric specialty center dedicated to childhood cancer and rare diseases—I write to express our strongest support for Senate Bill 348 (SB348). This legislation is a smart, evidence-based investment that will modernize Nevada's Newborn Screening (NBS) Program, delivering both measurable healthcare cost savings and improved outcomes for children and families across our state.

C4K provides care for thousands of children each year, managing hundreds of rare and ultra-rare genetic conditions—many of which could have been identified earlier through comprehensive newborn screening. Delayed diagnoses often lead to prolonged hospitalizations, expensive emergency care, and preventable lifelong complications. By advancing SB348, Nevada has the opportunity to not only improve survival rates but also achieve substantial cost savings by reducing avoidable hospitalizations, emergency interventions, and long-term care expenses for families, insurers, and the Medicaid system.

Investing in prevention is not only a sound healthcare policy—it is also smart economics. When resources are directed toward early detection and timely intervention, we minimize avoidable medical crises, lower healthcare spending, and ease the burden on an already strained system. SB348 ensures that Nevada's healthcare dollars are used where they have the greatest impact: preventing harm before it happens.

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1. The Economic Benefits of Early Diagnosis and Intervention

Studies consistently show that early detection through newborn screening is among the most cost-effective public health strategies. Notable findings include:

- MCADD screening: Benefit-cost ratio of 3.4 to 1, meaning every $1 spent saves $3.40 in long-term medical costs.
- Cystic fibrosis screening: Benefit-cost ratio of 4.0 to 5.4 to 1, showcasing high financial returns from early intervention.
- Cost-utility analyses: Newborn screening reduces special education needs, lifelong care expenses, and emergency medical interventions.
- Genetic screening: Associated with up to a 25% reduction in early disease-related mortality, preventing costly hospitalizations.

By passing SB348, Nevada will not only save millions in avoidable healthcare expenses but also empower families with timely diagnoses and access to critical resources.

2. Modernization of Newborn Screening Fees and Funding Model

To ensure long-term sustainability, SB348 introduces essential updates to Nevada's outdated funding model by:

- Establishing a $150 per-screening-kit fee, with automatic annual adjustments based on inflation.
- Supporting the expansion of the Recommended Uniform Screening Panel (RUSP) as new conditions are recognized.
- Enabling early treatment that reduces long-term healthcare burdens on families and the state.

This proactive approach ensures the program remains responsive, efficient, and financially sound for future generations.

3. Establishment of a Medical Genetics Program at Cure 4 The Kids Foundation

SB348 also funds the creation of a Medical Genetics Program at Cure 4 The Kids Foundation, giving Nevada families long-overdue access to expert, in-state genetic care. For decades, Nevada has lacked the infrastructure needed to properly diagnose and treat children with complex genetic conditions, forcing families to seek care out of state. This practice has placed a significant burden on families and the healthcare system, leading to:

- High travel and lodging costs
- Delays in diagnosis and initiation of care

- Increased emotional and financial stress for parents and caregivers.

By building local capacity through these dedicated genetics program, SB348 will reduce Medicaid expenditures on out-of-state referrals, close longstanding gaps in access, and ensure that children receive timely, high-quality, coordinated care right here in Nevada—at a lower overall cost to the state and families alike.

4. Licensure and Medicaid Coverage for Genetic Counselors

SB348 establishes a formal licensure process for genetic counselors and mandates Medicaid coverage for genetic counseling services. This will:

- Improve clinical decision-making by guiding families through complex diagnoses and care options.
- Reduce unnecessary testing, hospital visits, and ineffective treatments.
- Expand equitable access to critical services for all families, regardless of insurance status or income.

By investing in this workforce, Nevada strengthens its healthcare system while generating long-term cost savings across both public and private payers.

At Cure 4 The Kids Foundation, we see firsthand how early screening, expert diagnosis, and accessible treatment save lives while reducing long-term costs. SB348 is a rare opportunity to enact policy that is both a moral and economic imperative—reducing preventable suffering while ensuring that Nevada's healthcare dollars are spent wisely. Investing in early detection and local care is not just the right thing to do—it is the smart thing to do.

We respectfully urge you to support SB348. It is a smart, compassionate, and necessary step toward improving outcomes and managing healthcare costs for generations to come.

Sincerely,

Annette Logan-Parker

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Attached is a List of Supporting Studies RE: Cost Savings and Public Health Benefits of SB348

Supporting Studies for SB348 – Cost Savings and Public Health Benefits

The following studies provide evidence supporting the cost-effectiveness of newborn screening, genetic counseling, and local access to geneticists. These findings reinforce the importance of SB348 in improving healthcare efficiency and reducing long-term costs.

Cost-Effectiveness of Expanded Newborn Screening (NBS)

Cost-Effectiveness of the National Newborn Screening Program in Sweden
Evaluates cost savings and QALY gains from NBS for PKU and congenital hypothyroidism.

Link: Cost-Effectiveness of Newborn Screening for Phenylketonuria and Congenital Hypothyroidism - PubMed

Cost-Effectiveness of Expanded Newborn Screening in Texas
Analyzes the economic impact of implementing expanded NBS in Texas, concluding that such programs are cost-effective.

Link: https: pdf

Cost-Effectiveness of Newborn Screening for Severe Combined Immunodeficiency
Evaluates the cost-effectiveness and net benefit of implementing NBS for severe combined immunodeficiency (SCID).

Link: Cost-effectiveness of newborn screening for severe combined immunodeficiency - PubMed

Comprehensive Cost-Utility Analysis of Newborn Screening Strategies
Concludes that NBS is highly cost-effective, often leading to cost savings for society by preventing severe health outcomes.

Link: Comprehensive cost-utility analysis of newborn screening strategies - PubMed

Cost Savings of Early Access to Genetic Counselors

Cost-Effectiveness of Genome Sequencing for Diagnosing Patients
Genome sequencing is cost-effective compared to standard genetic testing, lowering cost per diagnosis.

Link: Cost-effectiveness of genome sequencing for diagnosing patients with undiagnosed rare genetic diseases - PubMed

Cost-Effectiveness of Returning Incidental Findings from Next-Generation Sequencing

Finds that returning incidental findings from genetic sequencing is cost-effective for certain patient populations.

Link: The cost-effectiveness of returning incidental findings from next-generation genomic sequencing

Cost Savings of Local Access to Geneticists

Reduction in Inappropriate Test Orders
Genetic counselors improve test order accuracy, reducing unnecessary testing and associated costs.

Link: https: Genetic counselor review of genetic test orders in a reference laboratory reduces unnecessary testing

Cost Savings Through Genetic Counselor Expertise
Utilizing genetic counselors leads to more accurate test orders and lower healthcare costs.

Link: Genetic Counselors Save Costs Across the Genetic Testing Spectrum

Improved Access and Reduced Costs via Telehealth

Telehealth-based genetic counseling increases accessibility while lowering overall healthcare costs.

Link: Revolutionizing Healthcare: How Telemedicine Is Improving Patient Outcomes and Expanding Access to Care - PMC