April 20th, 2026

The California Legislature
State Capitol, P.O. Box 942849, Sacramento, CA 94249-0001

Re: SB 1002 – Regarding Out of State Telehealth Services

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit a letter of support of SB 1002. The EveryLife Foundation for Rare Diseases is powered by the rare disease community to improve health outcomes by driving change through evidence-based policy, leading science-driven policy and regulatory research, activating the community to advocate for their rights and needs, and strengthening the rare disease community.

Many rare disease patients, especially those who are terminally ill, face physical and financial constraints in traveling to receive care. Advancements in telehealth platforms are making it easier for providers to diagnose, monitor, and treat diseases, without requiring those patients to travel long distances or take extensive time away from their work and families. Importantly, telehealth services can enable access to care across state boundaries, allowing rare disease patients to meet with expert physicians in other states. SB 1002 would provide an exemption to medical licensure requirements when providers treat terminally ill patients, providing desperately-needed access to medical care to the patients who need it most.

Expanding access to telehealth services can help ensure that the over 30 million Americans living with one or more rare disease can receive the expert clinical care they need.[1] Many patients do not have access to care close to home without telehealth, requiring patients to travel long distances. According to a 2019 survey, 39 percent of respondents needed to travel 60 or more miles to receive care, [2]creating physical and financial constraints that often contributed to missed work and school. For rare patients, 26 percent have reported missing school because of their rare disease and 62% of patients have been prevented from attending work.[3] Telehealth removes many of these barriers by allowing patients to receive care from home, better integrating care into someone's life.

Removing barriers to care through telehealth services can also reduce the time a patient waits for a diagnosis. A pilot program at Children's National Hospital in Washington DC using telehealth services was able to reduce the wait time for an appointment with a clinical geneticist from months to days.[4] This reduction in the diagnostic odyssey is valuable to rare disease patients who often wait years for a diagnosis. On average, it takes more than 6 years and nearly 17 doctor visits, hospitalizations, and other health-related trips, to receive a rare disease diagnosis after symptoms begin.[5] Telehealth can reduce this time by making it easier for patients to access visits.

Telehealth can also reduce the cost of care for rare disease patients and their families. Rare disease patients and families must navigate how to manage expenses from multiple inpatient and

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[1] National Human Genome Research Institute. (2019, March 9). *Rare Diseases FAQ*. Genome.gov. https://www.genome.gov/FAQ/Rare-Diseases
[3] See footnote 2.
[3] See footnote 2.
[4] Nothaft, W., Moore, G., & Cam, Y. L. (2022, September 13). Using telehealth to revolutionize the speed of making rare disease diagnoses. *STAT*. https://www.statnews.com/2020/08/27/telehealth-speed-up-diagnosing-rare-diseases/
[5] EveryLife Foundation for Rare Diseases. (2023, October 31). *Delayed Diagnosis Study - EveryLife Foundation for Rare Diseases*. https://everylifefoundation.org/delayed-diagnosis-study/

outpatient encounters, costs for prescription therapies and medical devices, and support services that are critical for their health and well-being. These costs can quickly add up. *The National Economic Burden of Rare Disease Study* determined the overall annual economic cost of rare diseases exceeded $966 billion in the year 2019 alone.[6] The study also found that in 2019, among individuals with the 379 rare diseases studied, the average adult incurred over $1,300 in travel expenses alone while seeking care or attending clinical travels.[7] Undoubtedly, the ability of physicians to reach rare disease patients in a convenient and cost-effective manner is important to reduce this economic burden.

SB 1002 ensures that rare disease patients can access telehealth services that will reduce travel time and expenses, while allowing patients to remain at home with their families in California. Please support SB 1002.

Sincerely,

Dylan Simon

Senior Director of Policy

EveryLife Foundation for Rare Diseases

Kathryn Poe

State Policy Manager

EveryLife Foundation for Rare Diseases

CC:

Michael Pearlmutter, Chief Executive Officer, EveryLife Foundation for Rare Diseases

Annie Kennedy, Chief Mission Officer, EveryLife Foundation for Rare Diseases

Amy Gaviglio, Chair, Board of Directors, EveryLife Foundation for Rare Diseases

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[6] EveryLife Foundation for Rare Diseases. (2025, October 7). *Burden study landing - EveryLife Foundation for Rare Diseases*. https://everylifefoundation.org/burden-study/

[7] EveryLife Foundation for Rare Diseases. (2025, October 7). *Burden study landing - EveryLife Foundation for Rare Diseases*. https://everylifefoundation.org/burden-study/