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January 28, 2025

Dear Chair Nosse and Members of the House Behavioral Health and Health Care Committee,

On behalf of the Fanconi Cancer Foundation (FCF), I am writing to express our enthusiastic support for HB2457, which seeks to establish a Rare Disease Advisory Council in Oregon. As an organization dedicated to supporting individuals and families impacted by Fanconi anemia—a rare genetic disorder with life-threatening consequences—we understand firsthand the critical need for coordinated care, resources and advocacy for the rare disease community.

Rare diseases, by definition, affect a small percentage of the population. However, the collective impact of rare diseases is significant, with over 25 million Americans living with one of the 7,000 known rare conditions. Fanconi anemia exemplifies the challenges faced by this community: delayed diagnoses, limited treatment options, and a lack of specialized resources. Establishing a Rare Disease Advisory Council in Oregon would provide a vital platform to address these issues and ensure that individuals with rare diseases and their families are not left behind.

HB2457 would bring together key stakeholders—including patients, caregivers, medical professionals, mental health professionals, and researchers—to identify gaps in care, promote education, and advocate for policy changes that prioritize whole person health and enhance the quality of life for individuals with rare diseases. By fostering collaboration and amplifying the voices of those impacted, the Council would serve as an essential bridge between the rare disease community and policymakers.

At FCF, we have witnessed the transformative power of advocacy and research in improving outcomes for individuals with Fanconi anemia. Yet, we also recognize that progress is only possible when there is a unified effort to address systemic barriers. The establishment of a Rare Disease Advisory Council in Oregon represents a meaningful step toward creating a more equitable and supportive healthcare system for all rare disease patients.

We strongly urge the legislature to pass HB2457 and demonstrate Oregon's commitment to addressing the unique challenges faced by the rare disease community. Thank you for considering this important initiative. If FCF can provide additional information or support, please do not hesitate to contact us.

Sincerely,

A handwritten signature in black ink, appearing to read "Jordan Deines", with a long horizontal flourish extending to the right.

Jordan Deines, LCSW
Director of Community Programs
Fanconi Cancer Foundation
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