FANCONI ANEMIA
RESEARCH FUND
Advancing Research. Supporting Families.

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February 16, 2017

The Honorable Peter Courtney
900 Court St. NE, S-201
Salem, Oregon 97301

The Honorable Tina Kotek
900 Court St. NE, Rm. 269
Salem, Oregon 97301

Dear President Courtney and Speaker Kotek,

The Fanconi Anemia Research Fund writes to you today to share its concern that proposed legislation, HB 2387, could potentially freeze the critical research work that is being done in Oregon to combat Fanconi anemia and other diseases.

Fanconi anemia (FA) is an inherited disease that can lead to bone marrow failure and cancer. Though considered primarily a blood disease, FA may affect all systems of the body. It is a complex and chronic disorder that is psychologically demanding. FA is also a cancer-prone disease, affecting patients decades earlier than the general population.

Lynn and Dave Frohnmayer started the Fanconi Anemia Research Fund in 1989 to find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide. Since its inception in 1989, the Fanconi Anemia Research Fund has sponsored more than 215 research grants in 63 laboratories worldwide. Donors to the Fund have seen their gifts multiply many fold in that pilot grants from the Fund have enabled many FA researchers to go on to receive major grants for FA research from the National Institutes of Health and other funding sources worldwide. Donations to the Fund have helped advance FA science more rapidly than ever thought possible.

As a society, we should support a policy climate that encourages investment in breaking the frontier of medicine. The gains to individual patients and society from new treatments are immense, and are simply not captured in the narrow focus on individual data points contemplated by these bills. Not only does innovation bring new hope to sufferers of deadly diseases, but they reduce costs across the health care system by reducing hospitalizations, surgeries, and doctor visits.

We appreciate the real challenges our health care system faces to keep costs down – and the complex factors that actually contribute to these costs. However, we believe HB 2387 does not take full account for the many factors—and stakeholders—that contribute to prescription drug costs. Numerous factors are at play, including robust negotiations between manufacturers, payers, and pharmacy benefit managers. A comprehensive bill should capture this complexity and consider the out-of-pocket costs that are of most

interest to patients; costs that are determined by the insurance plan rather than the manufacturer.

Instead, HB 2387 takes a singular aim at one segment of the issue and, in doing so, puts Oregon bioscience in the crosshairs. HB 2387 will force innovator companies to devote substantial time and resources to complying with burdensome requirements. Small biotech companies in particular may have to divert precious resources away from research and development activities to comply with these reporting requirements. Since these developers are the innovative industry's engine, this could mean delays in getting better treatments—and cures—to patients

As you work to tackle this complex issue, we hope you will take the following concerns into account. Drug costs must be addressed, but innovation and the development of better treatments and cures for deadly chronic diseases cannot be the casualty.

Thank you for your consideration.

Sincerely,

Cynthia Pappas
Interim Executive Director

cc: The Honorable Ginny Burdick
The Honorable Jennifer Williamson
Senate Committee on Health Care Members
House Committee on Health Care Members