March 20, 2025

Hon. Rob Nosse
Chair, House Committee on
Behavioral Health and Health Care

Hon. Cyrus Javadi and Travis Nelson
Vice Chairs, House Committee on
Behavioral Health and Health Care

Re: Support HB 3421 – Coverage for Biomarker Testing

Dear Representatives Nosse, Javadi, and Nelson:

I am Joanne McIntyre, I live in Southwest Portland, and I am here today to give my personal testimony, on behalf of **the American Cancer Society Cancer Action Network**, in support for **HB 3421.**

ACS CAN is grateful to Representatives Graber and Chotzen's leadership on this critically important live-saving issue. Biomarker testing saves lives and brings medical treatment to the level of Personalized, Precision care. Without it, health treatment outcomes are often compromised and can lead to suffering and sometimes death. The personal story I wish to share exemplifies that outcome.

In 2017 my husband was diagnosed with Cholangiocarcinoma (bile duct cancer), a rare and often fatal cancer. Because his tumor was diagnosed at an early stage, his doctors felt optimistic that his treatment would have a successful outcome.

David underwent a lengthy and difficult Whipple surgery to remove the tumor. Following his recovery from surgery, his Radiation Oncologist was so pleased with the outcome of his surgery that he declared David "Cancer Free" – saying as well "….go home and enjoy your life!"

We were beyond grateful and relieved to know that he had beaten the odds and could move on with his life. David's Medical Oncologist, however, felt that following up surgery with adjuvant chemotherapy was the best option and prescribed a round of capecitabine, a fluorouracil-based chemotherapy. For more than 40 years, capecitabine and its infusion form 5-FU have been the most widely used chemotherapies in the world

for breast, head and neck and GI cancers. But in order for the body to metabolize this chemo, a certain level of enzymes known as DPD (dihydro pyrimidine dehydrogenase) must be present. A deficiency in the DPD enzyme cannot be identified without testing as it is asymptomatic. Anyone with DPD enzyme deficiency taking this chemotherapy can get very sick or die. It is estimated that 1 in 20 people have DPD enzyme deficiency.

Exactly one week after starting the chemo, David began to experience side effects associated with the GI tract: diarrhea, vomiting, the beginning of mucositis and mouth blisters. After multiple calls to his oncologist's office, visits to the ER and hospitalization a week later, a doctor making rounds recognized his symptoms as DPD enzyme deficiency toxicity. The antidote for this toxicity, Vistogard, has a 98% cure rate if taken within 96 hours of the last dose of chemo. David was one week beyond that window when it was ordered, at a cost of $80,000.

Tragically, my husband died within 2 days of the last dose of Vistogard. He suffered excruciatingly painful, unimaginable side effects, including several strokes. His body was riddled with internal and external blisters and his mucositis was uncontrollable. His death would have been completely preventable had he received **a biomarker test** prior to starting the chemo to measure his DPD enzyme status. In fact, a simple cheek swab for $50 would have indicated that there was a potential deficiency. A $250 blood test would have identified his deficiency: *2A – the most common of the identified deficiencies. Instead, David endured unimaginable suffering, the financial cost was $500,000 in hospital expenses, and our family needlessly lost a husband, father and grandfather – all from the lack of a simple preemptive test.

Following David's death, I helped to form the advocacy group **Advocates for Universal DPD/DPYD Testing.** We are making strides in getting close to changing the standard of care to make upfront testing mandatory in the US. The EU and UK countries are well ahead of us in that regard. It is estimated that 700-1400 patients die annually in the US alone from 5-FU and DPD enzyme deficiency toxicity related to this chemotherapy. We are long past due in adding patient safety to the administration of this chemotherapy.

I urge you to advance **HB 3421** so that we can identify potential DPD deficient patients when being prescribed capecitabine and 5-FU so that they have a chance of surviving their cancer treatment rather than dying because of a lack of testing.

Respectfully,

Joanne S. McIntyre

Member, ACS CAN