



The Oregon Patient Rights Coalition

Support Senate Bill 1568

The Patient Protection and Affordable Care Act (PPACA) brought important reforms, improving access to health care and coverage. The law prohibits discrimination based on age, expected length of life, present or predicted disability, degree of medical dependency or quality of life.

Beginning January 1, 2017, states may apply for a federal waiver of one of the most important protections provisions of the PPACA that is set to expire; the anti-discrimination protections protection for people purchasing coverage through the health insurance exchange.

Under SB 1568, Oregon can preserve this protection and extend it to all who are insured by a state-regulated plan. All Oregonians deserve access to the best care available and strong protections against discrimination, regardless of their insurer.

SB 1568 will preserve, in law, these protections for Oregonians enrolled in health insurance exchange plans and extend the same protections to enrollees of the Oregon Health Plan and state-regulated private insurance plans.

The Facts on PPACA Section 1302:

- *The federal law requires that essential health benefits not be denied based on an individual's age, expected length of life, present, or predicted disability, degree of medical dependency, or quality of life.*
- *These essential health benefits must consider the needs of diverse segments of the population, including women, children, persons with disabilities, and other groups.*
- *Currently, these critical protections apply only to those Oregonians enrolled in health insurance exchange plans and may be waived by the federal government beginning in 2017.*

Join us and these organizations to protect your right to health care access.



Take Action:



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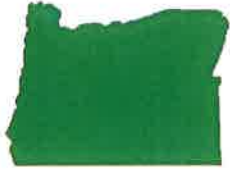


www.OregonPatientRights.org

The Oregon Patient Rights Coalition is a project of One in Four Chronic Health. One in Four Chronic Health is a non-profit organization registered with the Office of the Oregon Secretary of State.



For more information, contact BJ Cavnor at 503/ 208-9511.



The Oregon Patient Rights Coalition

February 11, 2016

Re: Organizational support for SB 1568

Senator Laurie Monnes Anderson
Chair, Senate Committee on Health Care
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Dear Sen. Monnes Anderson and members of the Senate Health Care Committee:

We are patient service and advocacy organizations, providing services to people throughout Oregon.

We are writing to share our support for SB 1568 and ask that the Senate Health Care Committee support passage of the bill in this upcoming 2016 legislative session. Your affirmative vote on SB 1568 will help protect the health of all Oregonians.

SB 1568 will codify some of the most important and critical protections of the Patient Protection and Affordable Care Act into Oregon state law.

These provisions include:

- Protections against discrimination based on a person's age, expected length of life, present or predicted disability, degree of medical dependency or quality of life;
- Extending of protections against discrimination to all Oregonians who are insured or covered under state regulated health plans, including Medicaid and commercial insurance plans, and
- Ensuring state-level enforcement of anti-discrimination provisions.

We are engaging on this issue now because we believe that preserving these protections requires immediate action. Currently, these protections apply only to Oregonians enrolled in health insurance exchange plans and may be waived by state application to the federal government beginning in 2017. SB 1568 will ensure all Oregonians covered by a state-regulate plan enjoy the same protections.

On behalf of the organizations listed below, thank you for scheduling a public hearing for SB 1568 and allowing us to share with you the reasons we believe the bill is so crucial to the health care of all Oregonians.

Sincerely,

One in Four Chronic Health

National Patient Advocate Foundation

Hemophilia Foundation of Oregon

Cascade AIDS Project

HIV Alliance Eugene

Oregon Health Equity Alliance

National Alliance on Mental Illness – Oregon

Arthritis Foundation, Great West Region

Disability Rights Oregon

Oregon Urological Society

American Cancer Society/Cancer Action Network - Oregon

Caring Ambassadors Hepatitis C and Lung Cancer Program



Madam Chair, distinguished members of the Senate Health Committee, my name is Madonna McGuire Smith. I have the privilege of serving as the Executive Director of the Hemophilia Foundation of Oregon and I am here today to testify in favor of SB 1568.

The Hemophilia Foundation of Oregon represents nearly 500 families and individuals living with bleeding disorders in Oregon and SW Washington. Hemophilia Foundation of Oregon enhances the quality of life for individuals with bleeding disorders and their families through advocacy, assistance, outreach, education and research support.

- **The two main bleeding disorders, hemophilia & von Willebrand Disease (VWD), are inherited bleeding disorders caused by a deficiency in proteins required for normal blood clotting. Patients use products made from human plasma or animal cells to replace proteins and control clotting.**
- **Many bleeding disorder patients were exposed to HIV and Hepatitis C prior to 1992 when the screening of blood products became the standard.**
- **It is estimated that as many as 70% of all individuals with bleeding disorders who used factor products before 1987 may have been exposed to HIV and as much as 90% were exposed to Hepatitis C.**
- **About 20,000 people are affected by hemophilia in the U.S. and approximately 1% of the U.S. population is affected by VWD.**

My husband and three children live with vonWillebrand Disease. Two of my children are severe and require regular infusions of blood product. Often our blood product bills can be more than \$150,000 annually. Although we have this hereditary disease, my children live a relatively normal life doing all of the same things other kids do across the US. In fact, we are fortunate to be living in the time we do because those with bleeding disorders now experience the same life expectancy of someone without the bleeding disorders.

The intent of SB 1568 is to "prohibit discrimination based on age, expected length of life, present or predicted disability, degree of medical dependency or quality of life in determination of medical services". These protections are currently guaranteed in the Patient Protections and Affordable Care Act (ACA). It is important to make these into Oregon law because states can waive these protections in 2017.

- **Extending these protections against discrimination to all Oregonians who are insured or covered under state regulated health plans, including Medicaid and commercial insurance plans, and**
- **Ensuring state-level enforcement of anti-discrimination provisions is the right thing to do!**

As a mom of children with a chronic medical condition, I understand certain discriminations when it comes to my children participation in some activities that can be dangerous throughout their lives. My son recently experienced discrimination in a school related situation. While it was difficult to understand as a family, we realize it was in the best interest of our son. He was applying to take part in a science trip to Costa Rica. The night before the names were to be announced we received a phone call from the organizing teacher. She wanted to warn us that after talking it over with the school district attorneys, administration and the Costa Rica camp managers, it was decided that our son wouldn't be able to attend

because of the risks. We discussed fighting the discrimination because of his bleeding disorder but decided it wasn't worth the fight. **There are times when discrimination is tolerable, not easy to take and difficult to understand, but tolerable.**

When it comes to discrimination in medical situations is not acceptable. If someone were to decide to deny one of my children proper medical care because they have a chronic bleeding disorder it would be intolerable. As stated earlier, people with bleeding disorders have the same life expectancy as anyone without a bleeding disorder. **SB 1568 would protect my children from medical discrimination in the future. Who has the right to deny someone proper medical care based on a perceived disability? SB 1568 doesn't mean that people will begin to dictate their medical care. On the contrary, Oregonians don't dictate their medical now, SB 1568 simply makes certain the current federal law is incorporated into state law and extended to all Oregonians.**



Debi Johnson

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February 11, 2016

Dear Madam Chair and members of the Senate Health Care and Human Services Committee

The Oregon Urological Society, composed of Urologists from throughout the state, strongly **urges you to support Senate Bill 1568.**

Patients should not be discriminated based on age, expected length of life, present or predicted disability, degree of medical dependency or quality of life in determining medical services covered under the medical retainer practice and in issuance of health benefit plans

It has come to our attention that our urology patients may be adversely impacted if the Oregon legislature does not act now to protect these patient rights by passing SB 1568. Without the passage it is our understanding that Oregon may apply for a waiver for the antidiscrimination provision within the Affordable Care Act that would impact Oregonians purchasing healthcare through the exchange when the provision expires on January 1, 2017.

Your support and passage of SB 1568 will send a message to all your constituents and Oregonians in general that your commitment to preserve access to essential health benefits.

The mission of the Oregon Urological Society is "To enhance the delivery and quality of urologic care through education and advocacy for patients and health care providers". It is with this in mind that we urge the passage of this bill.

Thank you for your consideration and please support and pass **SB 1568.**

Sincerely,

Debi Johnson
Executive Director
Oregon Urological Society

NPAF National Patient Advocate Foundation

The Patient's Voice | since 1996

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January 27, 2016

The Honorable Laurie Monnes Anderson
900 Court St. NE, S-413
Salem, OR 97301

RE: SB 1568 Protecting Oregon Patients from Health Care Discrimination

Dear Chair Monnes Anderson,

The National Patient Advocate Foundation (NPAF) is a national non-profit organization serving as the patient's voice in support of access to better quality, affordable healthcare. As the advocacy affiliate of the Patient Advocate Foundation (PAF), NPAF translates the individual experience of thousands of patients into national and state policy initiatives.

The more than 85,000 patients we serve each year from across the country represent a wide range of chronic, debilitating and life-threatening illnesses, and face significant and concrete obstacles to accessing healthcare in the U.S. Moreover, many of the patients served by NPAF and PAF come from lower income backgrounds, are often uninsured or newly insured, and have lower levels of health literacy.

I am writing on behalf of NPAF, PAF, and the Oregon patients we serve in support of SB 1568, legislation that will preserve the protections afforded by anti-discrimination provisions of the Patient Protection and Affordable Care Act (PPACA) for people purchasing insurance coverage through the health insurance exchange. The legislation will also extend those protections to Oregonians enrolled in the Oregon Health Plan and state-regulated private insurance.

The anti-discrimination provisions prohibit discrimination based on age, expected length of life, present or predicted disability, degree of medical dependency, or quality of life. Without these protections, essential health benefits required by some of the most vulnerable members of our community—women, children, and persons living with disabilities—may be lost or rendered unaffordable and out of reach. Currently, these critical protections apply only to those Oregonians enrolled in health insurance exchange plans and may be waived by the federal government beginning in 2017. SB 1568 would ensure that Oregonians will retain these important protections.

As Chair of the Committee on Health Care, we urge you to schedule hearings on SB 1568 as soon as possible so that we may educate members of the Committee on this important legislation. We look forward to working with you and, again, urge your support for SB 1568.

Sincerely,



Melissa Lorenzo Williams
Coordinator of State Government Relations