Testimony of Rep. Anne Larrivee, District 36, Gorham

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On February 15th two years ago, I sat in the conference room of a high risk pregnancy OB/GYN with my pregnant daughter and heard what no parent should ever have to hear -- that their child has cancer. (I'll tell you here that the child was 27, but as a mother she'll always be my child.) The weeks that ensued, my grandson's premature c-section birth, my daughter Susan's extensive surgery to remove the 25 lb. tumor and the stark realization of the seriousness of an infant in NNIC, the invasion of an aggressive ovarian cancer in my child, were the darkest and most hideous time of my life.

Medical science has brought us all a long way - the skill of the surgeon saved her life -- the 26 pints of blood she received were from healthy donors -- the IC saved an infant who would have not survived just a few years ago -- and the knowledge of the gynecological oncologist started her on a path of recovery, but not without a price.

The price for this hope of recovery is a treatment as aggressive as the disease. After Josh was delivered she was hospitalized for two weeks and just as soon as her sizable scar was partially healed she began a treatment regimen that could only be described as torture. For each treatment (16 days apart) she was hospitalized for 5 days with 3 aggressive IV drugs running all that time. At the

end of her treatments the veins in her hands and arms were as hard as rope, the platinum had poisoned her nervous system so that she had no feeling in her hands and feet (--she couldn't even feel the baby's soft skin.) She lost all her long blond hair, her white cell count dropped to 14, her skin felt like onion skin paper. And the nausea I won't try to describe. It set on her days before each treatment, it was excruciating during her hospital stay, and it dragged on after each treatment at the sight or smell of almost any food. And at the sight of any medical equipment -- an intermediate visit to the doctor's office was a nightmare for her. I pray that none of you ever have to watch someone you love go through this.

She had various drugs prescribed for the nausea - most of them had as a side effect diarrhea. She was particularly sensitive to them and I don't need to tell you that the last thing someone violently nauseous with barely enough strength to crawl to the bathroom needs is diarrhea. Of course, the treatment regimen calls for nourishing food and plenty of fluids just to withstand the treatment itself say nothing of healing from scars and surgery.

As a family we decided she should try marijuana - anything so she could keep a little soup down or a little juice. We had to decide who in the family could risk possible arrest or a criminal record. Her husband, a machinist at BIW, couldn't risk it -- they have very strict

rules -- his job and consequently their health insurance would have been gone in a heartbeat. Her brother, a researcher at Foundation for Blood Research in Scarborough, has been working on long term research projects with genetic markers for Downs Syndrome etc. He couldn't very well jeopardize the entire project with that stigma. My job doesn't lend itself well to illegal activity. We are expected to meet a higher standard than other citizens. My husband, her father, however, is self-employed. No boss to fire him, no insurance to lose, nothing to lose but a clean record and an upstanding life.

People shouldn't have to make those kinds of decisions just to help someone as sick as that child was.

The marijuana was not a cure-all, she did not miraculously gain strength and vigor, but she could at those times eat some food and I'm not sure how she could have survived the treatment without nourishment.

I don't take the podium lightly today - her story is painful to re-live and we all in the family have chosen to put it behind us in the joy we share in our healthy grandson, and in her complete remission. However, if one other family doesn't have to go through even any small part of what we did because this treatment is made available, it will have been worth our efforts today.