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**UNITED STATES DISTRICT COURT  
FOR THE DISTRICT OF NEW JERSEY**

JACOB GUNVALSON, CHERI AND JOHN  
GUNVALSON, AS GUARDIANS FOR  
JACOB GUNVALSON, AND CHERI AND  
JOHN GUNVALSON, INDIVIDUALLY,

Plaintiffs,

v.

PTC THERAPEUTICS, INC.,

Defendant.

Civil Action No. 08-3559 (WJM) (MF)

**DECLARATION OF  
MARK ANDERSON**

*Document Filed Electronically*

Mark Anderson, of full age, states as follows:

1. I am the Executive Director for an organization called the Barbara Schneider Foundation in Minneapolis, Minnesota. In 2001, I served as a Health Policy Director for United States Senator Paul Wellstone.

2. In 2001, Senator Wellstone and I met with Cheri and Jacob Gunvalson on the topic of Muscular Dystrophy. After several meetings it became apparent that little research was being funded by the federal government and that, compared to diseases with similar morbidity, muscular dystrophy had very little research support. Cheri and Jacob were very persistent and extremely energetic in their desire to get federal research dollars into companies such as PTC Corporation.
3. In 2001 Cheri and Jacob visited practically every member of U.S. House of Representatives and the U.S. Senate. They secured 49 co-authors to a bill sponsored by Senator Wellstone that would designate Centers of Excellence for muscular dystrophy research. The bill would also quadruple research funding for muscular dystrophy over a four year period. They also secured over 200 co-authors in the House of Representatives.
4. There is no doubt that the bill would not have been enacted but for Cheri and Jacob. Cheri and Jacob were the face of muscular dystrophy. By the end of the session, pictures drawn by Jacob were hanging in several offices, including the offices of Senator Spector and Senator Wellstone. But for the hard work of Cheri and Jacob I don't know if a bill would have even been introduced that year.
5. It was apparent to me that funding from the bill would underwrite research on a promising drug being developed by PTC Corporation.
6. Attached are the comments of Senator Wellstone on the Senate floor about

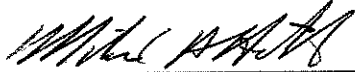
the good work of Jacob and Cheri.

Further your affiant sayeth not.



Mark Anderson

Subscribed and sworn to this 14<sup>th</sup>  
day of August, 2008.



Notary public



Currently, it can be very challenging for most Americans to find the information they need about their government. For example, if someone was looking for information on an issue pertaining to international trade, he or she would have to look at the web sites of the Department of Commerce, United States Trade Representative, International Trade Commission, possibly the Department of State or Agriculture, and a myriad of House and Senate Committees to find the information they seek. This process will undoubtedly frustrate the average American, and reinforce feelings of a remote, confusing government. Today, less than one percent of current interactions between government and citizens are online. There is clearly need for improvement.

This legislation will help create a coordinated government electronic policy. By establishing a Federal Chief Information Officer to operate within the Office of Management and Budget, the federal government will use staff and resources more effectively to promote e-government and address the nation's other pressing information policy issues. In addition, the bill establishes an Interagency Information Technology Fund to break down existing bureaucratic barriers, and set up a "one-stop shopping" portal that will make it easier for the public to access information. Finally, the bill will task the Office of Personnel Management to respond to the shortage of skilled Information Technology professionals in the federal government.

This bill is not simple, and I realize that some issues it raises must still be resolved. I believe that the Administration and relevant Congressional oversight committees must be involved in this process. I know that my colleague, the Chairman of the Government Affairs Committee, Senator THOMPSON, will examine this issue, and I would like to work with him to resolve any issues that he, or any other Member, may have with this legislation.

In conclusion, I urge my colleagues to support this legislation. It is important that we seriously examine how to use the Internet and other electronic commerce processes to make the federal government more open to public scrutiny.

By Mrs. FEINSTEIN (for herself, Ms. SNOWE, Mr. SCHUMER, Ms. COLLINS, and Mr. REED):

S. 804. A bill to amend title 49, United States Code, to require phased increases in the fuel efficiency standards applicable to light trucks; to require fuel economy standards for automobiles up to 10,000 pounds gross vehicle weight; to raise the fuel economy of the Federal fleet of vehicles, and for other purposes; to the Committee on Commerce, Science, and Transportation.

Mrs. FEINSTEIN. Mr. President, I am very pleased today to be joined by Senator OLYMPIA SNOWE to introduce

this important legislation to gradually phase-in the fuel efficiency standards for SUVs and light duty trucks by 2007.

I would also like to thank the other cosponsors: Senators CHARLES SCHUMER, SUSAN COLLINS and JACK REED.

Put simply, this is the single most effective action we can take to limit our reliance on foreign oil, save consumers at the pump, and reduce global warming.

Today, the U.S. has 4 percent of the world's population, yet we use 25 percent of the planet's energy.

So as the world's largest energy consumer, I believe it is our responsibility to make every effort to be the world's leader in conservation.

Specifically, the results of this bill would be substantial. It would: Save America one million barrels of oil a day; reduce oil imports by 10 percent; and prevent 240 million tons of carbon dioxide emissions from entering the atmosphere—this is the single biggest cause of Global Warming.

Today, the fuel economy standard for passenger vehicles is 27.5 miles per gallon, while the standard for SUVs and light duty trucks is 20.7 miles per gallon due to a loophole in the 1975 law.

The result: SUVs and light trucks now comprise nearly half of new car sales, bringing the average fuel economy of all the nation's new vehicles to its lowest point since 1980.

The Feinstein-Snowe legislation would: Phase in fuel economy standards for SUVs and all other light duty trucks on the following schedule: By 2002, SUVs and light duty vehicles must average 22.5 miles per gallon; by 2005, SUVs and light duty vehicles must average 25 miles per gallon; and by 2007, SUVs and light duty vehicles must average 27.5 miles per gallon; require that vehicles up to a weight of 10,000 pounds must qualify for fuel efficiency standards by 2007. The current limit is 8,500 pounds; increase the fuel economy of new vehicles comprising the federal government fleet by 6 miles per gallon by 2005.

Last year, former Senators Slade Gorton, Richard Bryan and I fought an uphill battle to try and find a way to increase these fuel economy standards.

But, we were stymied by the auto industry and their supporters in Congress.

Ultimately, at the end of the session, we reached an agreement that directed the National Academy of Sciences to study whether, in fact, we could raise fuel efficiency with sacrificing safety or competitiveness.

Recently, the automakers have said that they will not actively oppose increases in fuel efficiency standards.

The Big Three manufacturers have promised a voluntary increase in efficiency for SUVs by 25 percent by 2005.

This is an important step forward, but we need to do more. I believe this bill is the best way to do that.

By Mr. WELLSTONE (for himself, Mr. COCHRAN, Ms. COLLINS,

Mr. BENNETT, Mr. BREAUX, Mr. BUNNING, Mrs. CLINTON, Mr. CORZINE, Mr. DASCHLE, Mr. DAYTON, Mr. DORGAN, Mr. HUTCHINSON, Mr. JOHNSON, Mr. KERRY, Mr. KOHL, Ms. MIKULSKI, Mr. SARBANES, Mr. SCHUMER, Ms. SNOWE, Ms. STABENOW, and Mr. VOINOVICH):

A bill to amend the Public Health Service Act to provide for research with respect to various forms of muscular dystrophy, including Duchenne, Becker, limb girdle, congenital, facioscapulohumeral, myotonic, oculopharyngeal, distal, and emery-dreifuss muscular dystrophies; to the Committee on Health, Education, Labor, and Pensions.

Mr. WELLSTONE. Mr. President, this is the Muscular Dystrophy Community Assistance, Research And Education Act of 2001. It really is the MD CARE Act. I thank Senators COCHRAN and COLLINS, especially, for their assistance. There are 20 colleagues who support this legislation. It is about equally divided between Democrats and Republicans, thank God, because of what this piece of legislation is about.

To look at the record of research on these debilitating and deadly diseases is to realize that despite our country's enormous resources, sometimes people are left behind. Today, despite all the advances in medical science, victims of muscular dystrophy—which afflicts tens of thousands of individuals every year in America—have no cure and no effective treatments available to them.

I became engaged with the muscular dystrophy community when I was approached by several families in my home state of Minnesota with children suffering from Duchenne's muscular dystrophy (DMD). DMD is the most prevalent form of muscular dystrophy affecting children and it is the most deadly.

Children with DMD are most often not diagnosed before the age of two or three years. Because it is sex-linked, the disease only strikes boys but in reality, it strikes the entire family.

DMD children don't begin to walk until late, and then in an unusual manner. They frequently fall and have difficulty getting up. Climbing stairs is a major ordeal.

By age 9 these children start to rely on a wheelchair and by their teen years reliance becomes total.

Most tragically, the disease is characterized by a continued rapidly progressive muscle weakness that almost always results in death by 20 years of age.

I have three children, ages 36, 31, and 28. I cannot imagine this.

Children afflicted with Duchenne Muscular Dystrophy have no ability to produce the protein dystrophin, the protein that binds the muscle cells together. It is an exceptionally cruel disease that slowly robs boys of their independence and ultimately immobilizes them, leading invariably to an early loss of life.

Sadly, the federal response to this disease has been inadequate. This year, in an NIH budget of more than \$18 billion, research into Duchenne and Becker Muscular Dystrophies totals just \$9.2 million. Only \$17 million was devoted last year to all of the muscular dystrophies combined. If you want to understand why there is nothing available to treat DMD children, you need look no further than the weak federal response to this disease. The gene that is flawed in this disease is readily identifiable, and has been so for 14 years. Astonishingly, however, the pace of research on DMD actually slowed down after the gene was discovered.

One DMD child back in Minnesota that I have become especially fond of is Jacob Gunvalsen. Jacob is an adorable 10-year-old. He loves to play with his siblings out on his parents' farm, draw pictures for his family's refrigerator and play video games. Jacob and his mother Cheri Gunvalsen have made quite an impression on several members of Congress, and Jacob's picture adorns the desks of numerous health care legislative staff throughout Washington. This is because like so many other parents facing the day-to-day experience of living with a child suffering from this debilitating disease, Cheri is focused on leaving no stone unturned in her quest to help improve her son's chance of survival. One day, Jacob drew a picture of himself, and in a cloud above his figure he wrote the words, "What I want most in the world is a cure for Duchenne Muscular Dystrophy". I say to my colleagues, that's what I want, too. Today, we are getting one step closer to making Jacob's wish come true.

David Mesick, also of Minnesota, is the Chairman of the Parent Project Muscular Dystrophy, a national voluntary health organization committed to promoting medical research efforts specific to Duchenne and Becker muscular dystrophies. Through David's leadership and the organization's efforts, the muscular dystrophy community has successfully increased Congress' awareness of this devastating disease. Today, their voices are being heard here on the floor of the Senate. I have been moved by the number of families in Minnesota and elsewhere who have been affected by this disease, and I have been moved even more by their tenacious response. We can support this community by improving federal research efforts and public programs to address the needs of individuals with muscular dystrophy.

Mr. President, passage of this legislation will improve coordination of research not only into Duchenne's, but into all the various forms of Muscular Dystrophy. It authorizes the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) to establish separate Centers of Excellence to promote basic and clinical research, epidemiology, data collection and assessment on the various forms of muscular dystrophy. These

steps are needed to ensure a long-term commitment by the federal government to the treatment and cure of muscular dystrophy.

I am neither a scientist nor a physician. But I am told that it is highly probable that sooner or later gene therapy will be able to cure diseases of this nature. For diseases like Duchenne's muscular dystrophy, involving flaws on a single, identifiable gene, the outlook is even more positive. Yet the words 'sooner' and 'later' have profound consequences in the lives of tens of thousands of Americans and their families. With the introduction of the MD CARE Act, we move a step closer to giving those families hope. I encourage my colleagues on the Senate HELP Committee to work steadfastly to move this crucial legislation through the Senate, and I urge all colleagues to support it.

I also think of Eric Anderson who is such a good friend of my son. David and Eric came to Washington. So many of the families who came, and many came with their children, were so young and their children were so young. Time is not neutral for them. There is an excellent chance we can make a real breakthrough in finding a cure. It is not too much that these families ask for and it is not too much to pass this legislation and try and push forward a commitment to the funding, a commitment to this research.

This is one of those diseases. I hate to label, so few are affected, but for these children and these families, they are not too few in number. These are their lives. These are their hopes. These are their dreams. This is their pain. This is their agony. I want to turn this into hope. I ask all of my colleagues to support this legislation.

I am very pleased this has strong bipartisan support.

By Mr. HUTCHINSON:

S. 806. A bill to guarantee the right of individuals to receive full social security benefits under title II of the Social Security Act with an accurate annual cost-of-living adjustment; to the Committee on Finance.

Mr. HUTCHINSON. Mr. President, I ask unanimous consent that the text of Full Social Security Benefits Guarantee Act be printed in the RECORD.

There being no objection, the bill was ordered to be printed in the RECORD, as follows:

S. 806

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE.

This Act may be cited as the "Full Social Security Benefits Guarantee Act".

SEC. 2. GUARANTEE OF FULL SOCIAL SECURITY BENEFITS WITH ACCURATE ANNUAL COST-OF-LIVING ADJUSTMENT.

(a) IN GENERAL.—Not later than 90 days after the date of enactment of this Act, the Secretary of the Treasury shall issue to each individual who, as of such date, is receiving benefits under title II of the Social Security

Act (42 U.S.C. 401 et seq.) and, thereafter, to each individual who applies for such benefits, a certificate representing a legally enforceable guarantee—

(1) of the monthly amount of benefits that the individual will receive under that title, as determined on the date of the issuance of the certificate; and

(2) that the benefits will be adjusted—

(A) not less frequently than annually on the basis of an accurate determination of the increase in the cost-of-living of the individual; and

(B) as a result in a change in the eligibility status of the individual under that title.

(b) ENTITLEMENT.—Any certificate issued under the authority of this section constitutes budget authority in advance of appropriations Acts and represents the obligation of the Federal Government to provide for the payment to the individual to whom the certificate is issued benefits under title II of the Social Security Act (42 U.S.C. 401 et seq.) in the amounts set forth in the certificate and adjusted thereafter as described in subsection (a)(2).

By Mr. CORZINE:

S. 807. A bill to promote youth financial education; to the Committee on Health, Education, Labor, and Pensions.

Mr. CORZINE, Mr. President, today I am introducing the Youth Financial Literacy Act to address an important issue in education: teaching students the basic principles of financial literacy.

Unfortunately, when it comes to personal finances, young Americans do not have the skills they need. Too few understand the details of managing a checking account, for example, or using a credit card. It is time to make sure that our education system teaches our children all the skills they need, including the fundamental principles involved with earning, spending, saving and investing, so that they can manage their own money and succeed in our society.

We have just finished tax season, and a recent survey by the non-profit JumpStart Coalition reveals that the average high school student knows very little about how taxes will affect her take-home pay. The study also found that, on average, only 36 percent of surveyed high school students could correctly answer basic personal finance questions, and only 33 percent of students believed that financial issues strongly impacted their daily lives.

Young people today face an exceedingly complex financial system that is laced with pitfalls. Credit card companies lure naive college students, encouraging them to spend liberally. Music companies offer extraordinary deals such as "8 CDs for one penny!" and then trap customers into purchasing unwanted music every month. Many of our children are simply unaware of the dangers of these kinds of offers.

We also must make sure that the next generation is prepared to deal with the challenges they will find in the workplace. Rather than providing specific benefits, many companies are now encouraging employees to buy

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*Attorneys for Plaintiffs*

**UNITED STATES DISTRICT COURT  
FOR THE DISTRICT OF NEW JERSEY**

JACOB GUNVALSON, CHERI AND  
JOHN GUNVALSON, AS GUARDIANS  
FOR JACOB GUNVALSON, AND  
CHERI AND JOHN GUNVALSON,  
INDIVIDUALLY,

Plaintiffs,

v.

PTC THERAPEUTICS, INC.,

Defendant.

Civil Action No. 08-3559 (WJM) (MF)

**CERTIFICATION OF  
GENUINENESS OF SIGNATURE  
OF MARK ANDERSON**

*Document Filed Electronically*

MARC E. WOLIN, of full age, hereby certifies as follows:

1. I am an attorney-at-law of the State of New Jersey and a member of

the firm Saiber LLC, attorneys for Plaintiffs Jacob Gunvalson, Cheri and John Gunvalson, as guardians for Jacob Gunvalson, and Cheri and John Gunvalson, individually, in the above action.

2. The signature of Mark Anderson in his Declaration dated August 14, 2008, in support of Plaintiffs' Motion for a Preliminary Injunction, is genuine. If necessary or requested, upon my receipt thereof, the original signature will be filed with the Court.

/s/ Marc E. Wolin  
MARC E. WOLIN

Dated: August 15, 2008