

**S. 1509, THE PROPOSED ERIC AND BRIAN SIMON
ACT OF 2003**

HEARING
BEFORE THE
COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES SENATE
ONE HUNDRED EIGHTH CONGRESS
FIRST SESSION

MARCH 9, 2004

Printed for the use of the Committee on Veterans' Affairs



Available via the World Wide Web: <http://www.access.gpo.gov/congress/senate>

U.S. GOVERNMENT PRINTING OFFICE

20-730 PDF

WASHINGTON : 2005

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512-1800; DC area (202) 512-1800
Fax: (202) 512-2250 Mail: Stop SSOP, Washington, DC 20402-0001

COMMITTEE ON VETERANS' AFFAIRS

ARLEN SPECTER, Pennsylvania, *Chairman*

BEN NIGHTHORSE CAMPBELL, Colorado	BOB GRAHAM, Florida
LARRY E. CRAIG, Idaho	JOHN D. ROCKEFELLER IV, West Virginia
KAY BAILEY HUTCHISON, Texas	JAMES M. JEFFORDS, (I) Vermont
JIM BUNNING, Kentucky	DANIEL K. AKAKA, Hawaii
JOHN ENSIGN, Nevada	PATTY MURRAY, Washington
LINDSEY O. GRAHAM, South Carolina	ZELL MILLER, Georgia
LISA MURKOWSKI, Alaska	E. BENJAMIN NELSON, Nebraska

WILLIAM F. TUERK, *Staff Director and Chief Counsel*
BRYANT HALL, *Minority Staff Director and Chief Counsel*

C O N T E N T S

MARCH 9, 2004

SENATORS

	Page
Specter, Hon. Arlen, U.S. Senator from Pennsylvania	1
Coleman, Hon. Norm, U.S. Senator from Minnesota	1

WITNESSES

Simon, Douglas B., Veseli, Minnesota	3
Prepared statement	4
Simon, Eric M., Veseli, Minnesota	5
Prepared sattement	6

APPENDIX

Campbell, Hon. Ben Nighthorse, U.S. Senator from Colorado, prepared statement	9
---	---

**S. 1509, THE PROPOSED ERIC AND BRIAN
SIMON ACT OF 2003**

TUESDAY, MARCH 9, 2004

U.S. SENATE,
COMMITTEE ON VETERANS' AFFAIRS,
Washington, DC.

The committee met, pursuant to notice, at 2:44 p.m., in room SR-418, Russell Senate Office Building, Hon. Arlen Specter (chairman of the committee) presiding.

Present: Senator Specter.

Also present: Senator Coleman.

**STATEMENT OF HON. ARLEN SPECTER, U.S. SENATOR
FROM PENNSYLVANIA**

Chairman SPECTER. Good afternoon, everyone. We are here this afternoon to hear testimony from Mr. Douglas Simon, a man who has endured a family tragedy of a tremendous nature, and one of his sons, Eric Simon.

The plight of this family from Veseli, Minnesota, came to my attention through my very good friend, Senator Norm Coleman. I will defer now to Senator Coleman to introduce his constituents and to make a statement concerning their circumstances.

I do want to welcome both the elder and the younger Mr. Simon to this committee hearing room. We are anxious to hear your story, and not atypically, they have scheduled a vote, which can happen at any time, and when the bills ring for a vote, it takes precedence, even if we are in the White House.

Senator Coleman, thank you very much for your diligence here and welcome to this committee. We look forward to your presentation.

**STATEMENT OF HON. NORM COLEMAN, U.S. SENATOR
FROM MINNESOTA**

Senator COLEMAN. Thank you, thank you, Mr. Chairman. I want to begin by expressing my deep appreciation for Chairman Specter and his willingness to work with me, his deep compassion, and I am just very, very, very appreciative. This hearing would not have taken place without the actions of this great chairman. So Mr. Chairman, thank you very, very much.

During the early 1980s, when we were literally just beginning to learn what HIV/AIDS is and how it is transmitted, there were many, many individuals who contracted the disease through blood transfusions. Some of these individuals received tainted blood as a result of injuries sustained while serving in the United States

Armed Forces. Mr. Douglas Simon, who is here with us today, is one such individual.

Currently, the Veterans' Administration provides health care to some 2,800 veterans who have contracted AIDS in this manner. The VA also provides disability compensation to veterans with AIDS and death and education benefits to the families of veterans who succumb to AIDS. In this respect, the VA treats AIDS like other service-related health conditions.

However, in an important way, AIDS is not like other service-connected illnesses. AIDS can be directly transmitted to spouses and unborn children of the service members, as we will see.

Mr. Chairman, this is what happened in the case of Doug Simon. However, by law, the VA cannot provide any sort of benefits for illnesses contracted by these family members. I leave it to Doug and Eric Simon, and Eric will testify. Brother Brian is also here, so the family is here with us. But I leave it to Doug and Eric to share with the committee in detail the difficult experience with you. They can express what they have endured better than I can.

But I will tell you that this is a family that has suffered tremendously as the result of a service-related condition. Eric and Brian's mom, Nancy, succumbed to AIDS after a brave and long fight in 1996. Though they were much younger then, these boys had already been through a lot. This family also mourned the loss of Candace Simon, a beloved daughter and sister. This beautiful, innocent young girl was taken by this horrible disease in 1993, just three days before her sixth birthday.

This is tough stuff, very tough stuff, Mr. Chairman. This is a painful tale to tell, painful beyond words. But I share it with you to show what remarkable individuals sit before us today. These young men have lost their mother and their sister to AIDS and they have been tireless in taking care of their sick father. These two young men have had to grow up very, very quickly, Mr. Chairman, and words cannot convey how proud I am of Eric and Brian, talk about courage and talk about character.

Unable to receive justice from the courts, the Simon family is looking to Congress to correct this injustice. Last year, I introduced S. 1509, the Eric and Brian Simon Act, as a starting point for giving a fair deal to veterans and their families with AIDS. So S. 1509 would provide a one-time \$100,000 benefit to veterans who receive AIDS as a result of a blood transfusion from a service-related injury, spouses who contracted AIDS from contact with the infected veteran, and offspring of the veteran or spouse who are infected with HIV/AIDS at birth. In the event the veteran or family member has already succumbed to AIDS, the compensation would be given to survivors.

I would note, Mr. Chairman, there is precedence for this type of compensation. The 1998 Ricky Ray bill provided a one-time \$100,000 compensation to individuals and their spouses who contracted HIV/AIDS from hemophilia treatment. What I am proposing is that we give the same kind of assistance to the men and women who serve in our Armed Forces and their families.

Mr. Chairman, we have an obligation to care for our veterans and their families. It is my hope that after hearing our witnesses discuss the unique circumstances, the Congress will take a serious

look at developing a legislative fix to care for veteran with AIDS and their families.

With this goal in mind, I can't think of a better chair to have for this committee nor one more dedicated to our veterans than you, Mr. Chairman, and I look forward to working with you to right this wrong. Thank you once again for working with my office to hold this important hearing.

I am honored to introduce to the committee Mr. Douglas Simon, Mr. Eric Simon, accompanied by Mr. Brian Simon. Thank you, Mr. Chairman.

Chairman SPECTER. Thank you very much, Senator Coleman, for your outstanding work here and generally.

Thank you for joining us, Mr. Douglas Simon. We look forward to your testimony. You may begin.

STATEMENT OF DOUGLAS B. SIMON, VESELI, MINNESOTA

Mr. DOUGLAS SIMON. Chairman Specter, Ranking Member Graham, and other distinguished members of the committee, thank you for this opportunity to testify to you about the Eric and Brian Simon Act of 2003. It has been my goal to testify on Capitol Hill about my life and battle with HIV, which I contracted while serving our Army National Guard at Fort Benning, Georgia, in 1983.

I wanted to share three thoughts. First, I believe my family and others suffering the same horrible situation deserve compensation for the military mistake in not screening my blood transfusion. Shortly after my daughter Candace was born, I found out that I contracted HIV after receiving a blood transfusion at Martin Army Hospital. At first, the reality didn't sink in. Then my wife and I saw our baby daughter practically live her entire painful life in the Minneapolis Children's Hospital. Candace survived on morphine and would pray out loud to God that he would take her soon to heaven to stop the pain. It was terrifying to witness my baby girl dying so slowly and in so much pain.

Then the disease began to take its toll on me and my family. As a result of this disease, I have suffered strokes, encephalitis, staph, pneumonia, and loss of use of my bladder. I am basically a paraplegic and suffer deep depression and anxiety. Also, I take over 30 prescriptions per day. During the past 20 years, I have spent my life in and out of hospitals. My last hospital stay was January 2004.

Second, I know that they say life isn't fair, but it is unjust that I am unable to seek compensation because of a mistake made by the Federal Government and not a private hospital. I have been unable to sue for damages. It is like being punished for a crime I didn't commit.

Four months before my transfusion in 1983, April 1983, the military adopted guidelines of the Food and Drug Administration and recommended that people at high risk for contracting this virus voluntarily refrain from donating blood.

Third, I would have been able to live a healthy and full life if it were not for this transfusion. Instead, since my surgery, I have been unable to work. My life is rapidly diminishing. My wife and daughter have already died from HIV.

The Eric and Brian Simon Act of 2003 provides a gratuity to the veterans, such as myself, spouses, and their children who have contracted HIV or AIDS as the result of a blood transfusion related to a service-connected disability and for other purposes. This bill is right for veterans, spouses, and their children who have been harmed by serving their country. It provides a sense of justice and something to provide for my sons after my life has ended due to the military's mistakes.

I ask you to consider with common sense and compassion the Eric and Brian Simon Act of 2003. I thank you for your time. I am available for questions.

Chairman SPECTER. Thank you very much, Mr. Simon. Thank you very much for that very impressive testimony.

[The prepared statement of Mr. Douglas Simon follows:]

PREPARED STATEMENT OF DOUGLAS SIMON, VESELI, MINNESOTA

Chairman Specter, Ranking Member Graham, and other distinguished members of the committee. I would like to thank you for the opportunity to be here today to talk about the Eric and Brian Simon Act of 2003.

I am very lucky to be here today to speak with you, thanks to recent developments in medication to help fight the HIV/AIDS virus which quickly took my wife and daughter. I contracted the AIDS virus through a blood transfusion while serving our country in the National Guard at Fort Benning, Georgia in 1983.

The blood I received (nine pints) had the virus. Six months earlier, the FDA warned the military that blood was supposed to be screened but that didn't happen and the military was neglectful. Therefore, now I am here today bound to my wheelchair with the support and love of my two sons, Brian & Eric Simon.

We did not find out about the virus until my daughter, Candace, began getting sick. "Daddy, my tummy hurts" was a common complaint of my little girl. Candace Rose Simon began to deteriorate slowly and painfully while she was still a very little girl.

Tumors, coughing, and constant pain was hard for her. It tore me up inside to see such a beautiful angel go through something so terrible. It was also hard for my wife who has since passed away after Candace died. Nancy, my wife, contracted the virus through me and then onto Candace when she was born.

My two boys, Brian & Eric have been through hell watching their mother and sister die. I can't imagine two young boys going through so much pain and suffering.

No one deserves to go through this. There was a costly mistake made and so we've been paying for it with enormous amounts of pain. I want make sure that it doesn't happen. I believe there should be compensation made for this mistake.

The Eric and Brian Simon Act of 2003 provides justice and a form of compensation. I ask you to consider with common sense, compassion, and consideration the Eric and Brian Simon Act of 2003.

THE DOUG SIMON STORY

Doug Simon joined the Minnesota Army National Guard shortly after graduating from New Prague High School in Minnesota. In August 1983, while on active duty at Fort Benning, he had surgery at the Martin Army Community Hospital for sudden and severe bleeding.

To replace the blood he had lost, he required several transfusions. Investigators eventually tracked Mr. Simon's blood transfusion to nine donors, and one tested positive for HIV.

Four months before Mr. Simon's transfusions, the military adopted US Food and Drug Administration HIV/AIDS screening regulations. Mr. Simon returned home to Minnesota that December. Mr. Simon married his high school sweetheart, Nancy and the couple together dreamed about wanting a rambler home to share with four children and "a perfect rural Minnesota family life."

They lived together, in Mrs. Simon's hometown, Veseli, Minnesota, which has a population of 170. Mrs. Simon was a rural Minnesota homemaker and Mr. Simon started a career as a painter and wallboard installer. Mr. Simon enjoyed softball but within months of his transfusion was unable to play anymore softball because of his brain infection.

Together, Mr. and Mrs. Simon had three children, Brian, Eric, and Candace. Candace Rose Simon died of AIDS, three days before her sixth birthday. She contracted the virus either in utero or by breast feeding. "Daddy, my tummy hurts" was a common complaint of Mr. Simon's little girl and piercing words that he still clearly remembers. Candace was hospitalized 10 times during the last two years of her life.

"Tumors, coughing, and constant pain was hard for her. It tore me up inside to see such a beautiful angel go through something so terrible." Mr. Simon recalls.

Mrs. Simon became one of the nation's leading speakers on the HIV/AIDS virus before she died after twelve years of battling the virus. "Pretty soon everybody is going to know somebody with the AIDS virus," she once predicted.

Mr. Simon has spent his post-military life shuttling back and forth between his home in Veseli and hospitals in Minneapolis. He is now confined to a wheel chair and his two sons have become his caregivers.

Brian and Eric, have been through hell watching their mother and sister die and I can't imagine them going through so much more pain and suffering, Mr. Simon maintains.

Brian, age 18, is currently unemployed. Eric, age 17, is currently a senior at New Prague High and runs a landscaping and painting business to "make the ends meet." Daily, the two boys, give their dad medicine and lift him in and out of his wheelchair.

They cook the meals, wash clothes and pick their father off the ground when he falls from his wheelchair. They are not the typical teenagers, instead they have been children raising their father.

"No one deserves to go through this. There was a costly mistake made and so we've been paying for it with enormous amount of pain," Mr. Simon states. "I want to make sure that it doesn't happen again. I believe there should be compensation."

The Brian and Eric Simon Act of 2003 provides a gratuity, justice, and a sense of compassion, he concludes.

Chairman SPECTER. Mr. Eric Simon.

STATEMENT OF ERIC M. SIMON, VESELI, MINNESOTA

Mr. ERIC SIMON. Chairman Specter, Ranking Member Graham, and other distinguished members of the committee, I would like to thank you for the opportunity to speak to you today about my and my brother's bill, the Eric and Brian Simon Act of 2003.

I am 18 years old, a senior at New Prague High School in Minnesota. I have spent my entire life dealing with the effects of AIDS. In 1992, the first tragedy struck in my family when my baby sister died after fighting with AIDS through her short 5-year life. She and I were very close and I miss her very much.

Next, in 1996, my mother, who was everything to me, took her last breath while I was sitting next to her on her bed. She had a very painful experience with HIV. She went from not being able to care for her sons to losing her eyesight, and then not being able to walk, and then eventually not being able to talk. So now at this point, I had lost half of my family and all I could think about is when I would lose the other half.

Today, I would like to share with you three thoughts. First, I believe my family and others suffering with the same horrible situation deserve compensation for the military's mistake that led to my father contracting HIV. I am not the typical teenager. Instead, I own and operate my own small business to pay some of the family's bills. I help my father get dressed and make sure he gets his medications daily.

I haven't been able to enjoy typical teenager activities. Instead of playing hockey or other sports, I research the Internet, learning about AIDS. I am caregiver for my father while trying to cope with an illness that has killed my family. I have had to witness burying

two loved ones, and once every 2 weeks I typically bring my dad to the hospital for appointments.

Sometimes I have to bring my dad to the hospital at 1 o'clock in the morning. I have been on call my entire life. Sometimes I skip school to take care of my dad. I cook two meals a day and I have had to be an adult taking care of my dad. It has been hard to focus on schoolwork when my brother and I are constantly caring for our father and worrying about his health and how long he will be with us. He is my dad and I love him.

Second, I may be a kid, but even I realize that my family was wronged, and it is only right that we would receive some sort of compensation. We can't file a wrongful death suit because of legal rules. We can't collect any money. Do you think that is right?

Third, I ask for your support and consideration. No one can change my life, and I won't kid you. It has been hard. I pray each day for my father's health. This is a bill that is right for veterans, spouses, and children who have been harmed by service to their country.

Today, I have told you what my childhood has been like. Since 1996, I have been raising my dad and taking care of him. I love my father. Living with AIDS is a painful, tragic thing that creates fear, uncertainty, and sometimes hopeless dreams.

I ask you to consider with common sense, compassion, and consideration the Eric and Brian Simon Act of 2003. Thank you for this excellent opportunity today, and I am available for your questions.

Chairman SPECTER. Thank you very much, Mr. Eric Simon.
[The prepared statement of Mr. Eric Simon follows:]

PREPARED STATEMENT OF ERIC SIMON, VESELI, MINNESOTA

Chairman Specter, Ranking Member Graham, and other distinguished members of the committee. We greatly appreciate the excellent opportunity to come and give testimony for the Eric and Brian Simon Act of 2003.

In 1983, my father, Doug Simon, was training in the Army National Guard at Fort Benning in Georgia. During training he became ill and required surgery. During his operation he received a blood transfusion. The blood he was given was tainted with the AIDS virus which had not been properly screened. My mother, Nancy, was pregnant with my older brother, Brian. I, their second son, was born two years later with a high risk of contracting the virus, but I didn't contract the disease.

Our family didn't learn about the nature of this terrible disease until my little sister Candace (who was born in 1988) became terribly ill. Our whole family was then tested and all but my brother and I tested positive for HIV. Reality did not sink in for my parents right away. My brother and I were still very young. From the time, we found out about our misfortune to the time of my sister's death at the Minneapolis Children's Hospital in Minnesota, we had dealt with very much sadness and pain.

Candace was only a baby girl and she made her home at the hospital. The rest of us often lived there as well. Candace's pain took a toll on everyone. Why does someone that young have to deal with something so large? Candace prayed to God to take her to heaven so she would have no more pain and I'm very glad God took her to heaven and stopped her pain, but it still left a deep wound in all of our hearts.

As my brother and I were getting older, we were realizing what our life was turning into, a nightmare that we would never wake up from. We still didn't know what path in life we would be forced to take since we had two parents that were starting to feel the affects of the disease. I grew up around cameras and newspapers which gave me a lot of attention, but why did it have to be this type of attention? Why not for a star player at a baseball game or for saving someone's life?

I remember having to bury my sister. I will always remember that. My mother was becoming very ill in 1996 and was no longer able to care for her two sons and the motherly role was passed on to my grandmother and my aunt.

My parents were split up because of my sister's death and that just made it twice as hard on my brother and me. My mother had wanted to die out at my aunt's farm by New Prague, Minnesota. So we moved there to wait for our mother's death. Every day consisted of the same thoughts; thoughts of my mother dying and no longer being able to hug me and hold me.

She began to lose her eyesight so she couldn't even see the Mother's Day present that we made her in school. She could no longer stand or go to the bathroom herself. She was in fear of death but on the other hand she was excited to finally be with her baby daughter in heaven. She had a morphine pack that she was able to push a button and the morphine was electronically injected into her and that's how she survived the pain. But, eventually nothing worked. She would cry and cry and she became delusional on the thought of death.

My brother's and my mind were spinning in circles. We didn't know who to talk to or what to say or even where to turn. Eventually, my mother went into a coma and as weeks went on she began to look like a skeleton and while I was next to her bed on that afternoon, my mother, my everything, took her last breath. Since that day I have not cried, I have seen it all and been through it all and I have no more tears left to shed.

After the death of my mother, my brother and I moved in with our father at his parent's house. My father had suffered a stroke and was bound to a wheel chair. The only thought that was going through my mind was how can I handle anymore death?

Is it even possible? So I feared for my father's death and I still do everyday when I wake up in the morning and every night when I go to bed.

During each day, my brother and I are my father's caregivers and his life. We cook meals, wash clothes, make sure he takes his pills, we pick him off the ground when he falls, drive him to the hospital weekly and we still manage to have a normal life, or at least try to have a normal life. I love my father very much and I'm the most thankful person in the world to have what I have today, because my father is everything to me.

This is my life story and the way it has been for me and still I'm very thankful.

I ask you to consider the Eric and Brian Simon Act of 2003 to help my family and to help any other families in the same situation as mine and to also protect people and families that may fall victim to the same military mistake in the future.

Veterans are what make this country our country, they protect it and insure our safety, and to not consider this bill for my family and for a military veteran would be wrong.

I ask you again to consider with common sense, compassion and consideration, the Eric and Brian Simon Act of 2003.

Thank you for your time.

Chairman SPECTER. Thank you, Mr. Douglas Simon, for your service as a Reservist. The Reservists are bearing the brunt of the war today in Iraq and Afghanistan and being called around the country. So there is no doubt about your great service to your country. Thank you, Eric, for taking care of your father.

My inclinations are to support Senator Coleman. Before making a final decision, I want to review to see what the financial impact would be on the government—which is something we have to consider—how many people would be similarly situated. But there is no doubt. You are being given disability, but that is hardly adequate for what has happened and we understand that and there are potential benefits for your sons' education only under certain circumstances.

We are about out of time. The vote has just occurred. I think we have a full grasp of what is involved here and we will consider it very, very carefully.

Again, I thank you, Senator Coleman, for bringing this to the committee's attention.

Senator COLEMAN. Thank you, Senator Specter. Again, votes kind of rule our timing and our life. I am told we have less than a minute left.

Just a note. Mr. Simon would tell you that his care, his VA care, was good. He got great health care, excellent. But the reality is, this is a family that has never received an apology from the government. His mom died, his wife, daughter, and sister died and find themselves unable to receive anything to compensate them, and certainly money can't compensate, but the reality is this family has been through some very difficult circumstances, Mr. Chairman.

I want to thank you again for allowing them to tell the story as part of the official record. We will share it with other members and hopefully go forth from here.

Chairman SPECTER. Thank you, Senator Coleman, and thank you, Mr. Simon and Mr. Simon. Thank you.

We are going to run now. We have a vote and have to show up on the Senate floor. The hearing is adjourned.

[Whereupon, at 2:58 p.m., the committee was adjourned.]

A P P E N D I X

PREPARED STATEMENT OF HON. BEN NIGHTHORSE CAMPBELL, U.S. SENATOR
FROM COLORADO

Good morning, Mr. Chairman. I thank you for convening this hearing in which we will hear testimony on Senator Coleman's bill,

S. 1509, which would provide benefits to veterans who became infected with AIDS in the service from blood transfusions. It would also provide benefits to the veteran's family members who contracted the disease from the veteran.

I understand that these benefits would be provided from mandatory funds and that there is no precedent for VA to payout lump sum compensation benefits to veterans or their family members. I further understand that the legislation is modeled after the Ricky Ray Hemophilia Relief Act of 1998.

The fact that a number of veterans were given contaminated blood while in the service of their country is tragic. And, I believe the VA had an obligation to inform anyone immediately upon the discovery of such a situation. However, there are a number of questions that will have to be explored as we consider this legislation. How many vets have contracted AIDS through service-connected transfusions? Who will have the burden of proof that the AIDS virus was contracted by transfusion?

As a cosponsor of S. 1143, the Hepatitis C Epidemic Control and Prevention Act, I know that many people with HIV are also co-infected with Hepatitis C. Should the VA compensate family members who contract Hepatitis C from a veteran?

I welcome Mr. Simon and his son Eric. I look forward to their testimony as we begin to explore this issue.

Thank you, Mr. Chairman.

○