

**THE LYMPHOMA RESEARCH FOUNDATION OF AMERICA****WITNESSES**

**HON. STEVE HORN, A REPRESENTATIVE OF CONGRESS FROM THE  
STATE OF CALIFORNIA  
GENEVIEVE DOUGLASS**

Mr. HORN. Madam Chairman, I am honored to introduce to you one of our top leaders in the community, Genevieve Douglass. She had to bury her husband from lymphoma. It was attributed to Agent Orange. And so what we would hope is that this Subcommittee could recommend more research on that by the VA and it should also be in the NIH because they need to work together in terms of the genetics and everything else. So I would hope that you could hear her story.

Mrs. NORTHRUP. Thank you, and welcome.

Ms. DOUGLASS. Thank you, Madam Chairperson. Thank you for the opportunity to present public testimony on behalf of the Lymphoma Research Foundation of America. LRFA is a private, nonprofit foundation and a leading lymphoma resource in the United States. The Foundation funds research and has awarded \$3 million to support 90 research projects. I am Genevieve Douglass, the widow of Vietnam Veteran Bob Douglass. In addition to membership in LRFA, I cofounded the Agent Orange Widows Awareness Coalition with my friend Karen, who is here with me today, and is the widow of Robert Olszewski, another Vietnam veteran.

Both our husbands died recently of Agent Orange-related lymphoma. It is with great honor and humility that we speak to you today on behalf of the Foundation, Agent Orange Widows Awareness Coalition, Vietnam veterans and their post-war children across the Nation.

I bring to you the story of my husband, Bob, who died last year. His death was 100-percent service connected as a result of this exposure to Agent Orange, the defoliant used in Vietnam. I am testifying to respectfully request your support of expansion of the Veterans Administration research portfolio on lymphoid malignancies.

Lymphoma is the second fastest-growing incidence of cancer in America. It is estimated that over 87,000 Americans will be diagnosed this year with lymphoid malignancies, with a 50-percent mortality rate. Hodgkin's and non-Hodgkin's lymphoma are two of the ten diseases and conditions recognized by the VA as service-connected for Vietnam veterans because of their exposure to Agent Orange.

Bob served in Vietnam from 1969 to 1970 as a cook in a base camp near Da Nang. In August of 1997, he discovered a small lump on the side of his neck. A biopsy revealed an aggressive-type of non-Hodgkin's lymphoma. Within 2 weeks, the lump had grown so

fast that it blocked Bob's breathing and forced him on a liquid diet. He lost 25 pounds and his voice all within the first month of diagnosis.

In trying to figure out how Bob developed lymphoma, we recalled hearing news stories about Agent Orange-related illnesses. When we asked our doctors if they knew of the connection, they did not. In August of 1998, after a recurrence of Bob's lymphoma in his liver, we sought a second opinion at UCLA medical center. They also were unaware of the connection to Agent Orange-related diseases. A more aggressive treatment of chemo was recommended.

At this point, we contacted the Lymphoma Research Foundation. Finally, they knew of the connection to Agent Orange. We then went to the VA Hospital to enroll, but had to wait 6 weeks for an appointment with the Agent Orange Registry doctor. Bob's lymphoma took a turn for the worst on February 10th. Nine days later, Bob died at the age of 49, leaving me a widow and our two sons, Shawn and Corporal Daniel Douglass, fatherless.

Although we are now in the year 2000, currently, the VA has limited resource information regarding Agent Orange and lymphoma. Over 3 million troops served in Southeast Asia during the Vietnam War, when an estimated 19 million gallons of chemical defoliants were sprayed. The VA acknowledges that all veteran Vietnam personnel were exposed. There is insufficient research and data to determine the true relationship between Agent Orange and the second- and third-generation lymphoma cases.

It has been 25 years since the end of the war. We now have a generation of veterans who are getting sick and dying across the Nation, leaving families devastated, in grief, despair, and financial distress. The United States Government is failing the people who served our country.

On behalf of the Lymphoma Research Foundation, I ask for your assistance with the Foundation's request for expansion of VA resources and increased funding of Agent Orange-related lymphoma research regarding the development, diagnosis and treatment of the disease in Vietnam Veterans and their post-war children.

This is a picture of my friend Dixie Miller's husband in the middle of the jungle where Agent Orange was sprayed, and you can see everything is dead around him, and they worked with very little protection. This is my husband, Bob, and this is our T-shirt with the Agent Orange Widow's Awareness Coalition and all of our ladies get to put their husband's pictures on the back of it. And this is Karen Olszewski's husband, Robert Olszewski.

And so please seriously consider our request, as we try to assist veterans with lymphoma whom must face the challenge of fighting for their lives once again.

Thank you for your attention to this important issue. I would be happy to answer any questions.

[The information follows:]



**LYMPHOMA RESEARCH FOUNDATION**

**Of AMERICA, INC.**

**Testimony of**

**Genevieve Douglass**

**on behalf of the**

**Lymphoma Research Foundation of America**

**Before the**

**House Appropriations Subcommittee**

**on**

**VA-HUD**

**Thursday, April 13, 2000**

**3:05 p.m.**

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to present public witness testimony on behalf of the Lymphoma Research Foundation of America (LRFA). LRFA is a private, non-profit foundation, founded by Ellen Glesby Cohen in 1991 after being diagnosed with non-Hodgkin's lymphoma. The Foundation is the leading lymphoma resource in the United States, providing information and support to lymphoma patients and their families as well as funding for lymphoma research. To date, the Foundation has awarded close to \$3 million to support 90 research projects.

I am Genevieve Douglass, the widow of Vietnam Veteran, Bob Douglass. In addition to being a member of LRFA, I also Co-founded the Agent Orange Widows Awareness Coalition (AOWAC). It is with great honor and humility that I speak to you today on behalf of the Foundation, AOWAC, and Vietnam Veterans and their family members across the nation. I bring to you the stories of my husband, Bob and others who suffer and die from lymphoma. Bob's non-Hodgkin's lymphoma was service-connected and caused from exposure to herbicides, such as Agent Orange, used in Vietnam over 30 years ago. I am testifying to respectfully request your support for the expansion of the Veteran's Health Administration research portfolio on lymphoid malignancies.

According to a March 14, 1996 press release from the National Academy of Sciences, "New evidence supports the association between chemicals used in herbicides in the Vietnam War and various other cancers and other health problems, a committee of the Institute of Medicine (IOM) said in the first update of IOM's 1994 landmark report on veterans and Agent Orange." The report confirms that there is sufficient evidence to link non-Hodgkin's lymphoma and Hodgkin's Disease to exposure to Agent Orange. Hodgkin's and non-Hodgkin's lymphoma are two of the ten diseases recognized by the Veterans Administration as service-connected for Vietnam veterans based on exposure to Agent Orange and other herbicides.

My husband Bob served in the Army from 1967-1970. From 1969-1970, he served in Vietnam for 14 months as a cook in a base camp near Da Nang. We met after his return to the United States in 1970 and were married later that year. We had two sons, Shawn and Daniel.

In August 1997, Bob discovered a small lump on the side of his neck. A biopsy revealed an aggressive type of non-Hodgkin's lymphoma. Within two weeks, the lump had grown so fast that it blocked Bob's breathing. As a result of the rapid tumor growth, Bob was forced to go on a liquid diet, lost 25 pounds and his voice, all within the first month of his diagnosis.

Because Bob was young and healthy, we were told that there was a good chance he would respond to treatment, which would consist of chemotherapy and radiation. The tumor responded to the treatment and shrunk to a mere trace. Towards the end of May 1998, Bob was told he was in remission and was given a clean bill of health. He continued to be monitored.

In trying to figure out how Bob contracted lymphoma, we remembered stories of other veterans and their disease connections to Agent Orange exposure during military service in Vietnam. We specifically asked our team of physicians if there was a connection between non-Hodgkin's lymphoma and exposure to Agent Orange during the Vietnam War. They replied that they were not aware of any connection.

In August of 1998, Bob started having discomfort in his stomach. His doctors discovered a recurrence of the lymphoma in Bob's liver. A more aggressive treatment of chemotherapy was recommended. We sought a second opinion at the University of California Los Angeles (UCLA) Medical Center. The doctors at UCLA agreed with Bob's diagnosis and the treatment prescribed by our doctors. The immediate goal was to get Bob as close to remission as possible and then perform a stem cell transplant. Bob was very brave, and his positive attitude and faith in God helped to sustain our family.

Once again, we specifically asked the UCLA research doctors if they knew of any possible connection between lymphoma and exposure to Agent Orange during service in Vietnam. They gave a shrug of the shoulders and answered, "No."

In November of 1998, Bob began to receive high-dose chemotherapy treatment. At this point I had many unanswered questions and contacted the Lymphoma Research Foundation of America for information and support. The Foundation informed me of the service connection between Vietnam Veterans and lymphoma.

We went to the VA hospital to enroll in the general registry, which allows Veterans access to services. We were not automatically offered a referral to the Agent Orange Registry, but requested a referral to review Bob's medical diagnosis of lymphoma. We had to wait six weeks before getting an appointment for an Agent Orange clinical exam at the Long Beach VA hospital. It was very frustrating because Bob was no longer responding to treatment and our oncologist wanted to talk with a VA oncologist to see if there were other treatments being successfully used in Vietnam Veterans with lymphoma. We assumed the VA doctors would be the experts on the disease because of the link between lymphoma and Vietnam Veterans. Unfortunately, the Agent Orange exam was not performed by an oncologist, but by a general practitioner.

I called the Long Beach VA's oncology department to see if we could have Bob's case reviewed. After filling out paper work related to Bob's Vietnam service and a check up with a VA physician, Bob's file was stamped Agent Orange and we were referred to the Disability Benefits office to file a claim.

A week later, Bob's medical file was reviewed by a VA oncologist and treatment with Rituxan, a relatively new monoclonal antibody being used to treat non-Hodgkin's lymphoma was recommended. Bob began Rituxan in mid January of 1999. His treatment regimen was to consist of weekly treatments for four (4) weeks followed by a possible second series of Rituxan and then a stem cell transplant. It was our only hope at the time and we did have hope.



Bob finished his first series of Rituxan and was getting ready to have a CT-scan, when he took a fast downward spiral on February 10<sup>th</sup>. Nine days later, on February 19<sup>th</sup>, Bob suddenly died at the age of 49, leaving me a widow and my two sons, Shawn and Daniel, fatherless. Our sons and future grandchildren will miss out on life with Bob. He would never get to be a grandfather and he would have been a great one, that's for sure. I have had to experience widowhood and at the same time the empty nest stage of my life, all alone, without my loving husband, Bob.

Four months after Bob passed away, his VA disability was approved, but because he only lived for 7 weeks after the claim was filed, he only received one month of compensation for his eighteen month long illness. Our nation's medical community does not know of the connection between lymphoma and the other diseases associated with veterans who served in Vietnam. Because of this, our veterans and their families suffer needlessly.

Bob worked up until a week before his death just to keep his health coverage and provide income for his family. If our medical communities had known about the service-related link to lymphoma, Bob could have gone on disability when he was first diagnosed. Our family's needs would have been provided for, allowing Bob to concentrate on his health and recovery. If we had been properly informed about Bob's chances of survival, we would have made different decisions, spent more time together, and perhaps would have been better prepared for the inevitable, Bob's death from lymphoma.

Although we are now in the year 2000, the Veteran's Health Administration is conducting little research on lymphoma. According to the VA, 219 cancer research projects were conducted in fiscal 1999 totaling \$26.8 million. Of that amount, 15 research projects were conducted on lymphoma, totaling \$1.6 million. The VA estimates that 3.1 million veterans served in Southeast Asia during the Vietnam War, where an estimated 19 million gallons of chemical defoliant were sprayed. The United States government has a responsibility to help America's veterans suffering from service-connected diseases and is failing the veterans who have or will contract lymphoma.

Through my advocacy work with the Lymphoma Research Foundation of America, I discovered that lymphoma researchers did not know of the connection between Vietnam veterans and lymphoma. Therefore, research is not being conducted that would shed light on the link between the development of lymphoma and exposure to chemicals like Agent Orange, which in turn, would lead to more effective treatments and a cure for the disease.

In previous studies, it seems that the VA has conducted statistical data research and only minimal research on lymphoma itself. In fact, based on the limited information I have been able to obtain, it seems the VA has little data on the disease and how it has affected the lives of Vietnam veterans. It has been over thirty years since the beginning of the war and this is just not acceptable. Our veterans and their families deserve much better health care and respect for serving our country in the preservation of freedom. We now have a

generation of veterans that are getting sick and dying across the nation, leaving families devastated in grief, despair, and financial distress. We must do better for them.

It is my understanding that only 25% of veterans use the VA Medical system nationwide. The VA can and must do more to reach and inform veterans of the medical health risks and benefits that are available to those who qualify. The VA needs to communicate with the civilian medical community to spread the word on service-connected diseases and implement a national awareness campaign to educate veterans and their families.

Even the oncology department of the San Diego Navy Hospital was unaware of the list of diseases associated with military service. My mother-in-law, Bob's mom, Irene Frey volunteers at the Navy hospital in the oncology department and has taken it upon herself to educate the doctors there about these service-connected diseases. She is seventy-four years old. This is amazing, isn't it?

I have talked with other Vietnam veterans, their widows and family members across the nation who are hurting and in the dark. I met a woman, Karen Olszewski, at a Long Beach Stand Down, an annual outreach program targeting homeless veterans, who calls herself an Agent Orange Widow. Karen's husband, Robert Olszewski, another Vietnam veteran, died in 1996 from lymphoma. I said to myself, "Is that what I am, an Agent Orange Widow?" Yes, I am. Karen and I decided that we knew too much to keep silent and launched an organization called the Agent Orange Widows Awareness Coalition (AOWAC). Our mission is to educate veterans, their families, and the medical community about service-related diseases and the availability of medical health benefits from the VA. We want to build a partnership with the VA and work together with our Congressional Representatives to better serve our military veterans.

Since I founded AOWAC I have been on a quest for information about lymphoma and what information the VA has on the disease. The VA has little information about lymphoma due to lack of coordination. For example, the local Agent Orange / Persian Gulf Registry Offices in the VA's Medical Centers do not enter the disease diagnosis of Veterans in their databases. Instead, this information is forwarded on paper to Washington, DC for entry into the national VA Agent Orange Registry. It seems logical for this information to be entered into the databases of all the registries so that those who need to access the information may do so conveniently and in a timely manner.

I discovered that the Cancer Registry and the Agent Orange Registry are not cross-referenced for meaningful statistical documentation. Therefore, many cases of Agent Orange exposure have been entered into Agent Orange Registries, but the cancer cases in this population at risk have not been captured into Cancer Registries. The VA cancer registries have these data only as of 1999. This should be corrected. There is also little data to determine whether there is a link between a diagnosis of lymphoma in someone who has served in Vietnam and second and third generation lymphoma cases.

On behalf of the Lymphoma Research Foundation of America, I ask for your assistance with the Foundation's request for expansion of VA resources and increased funding of

lymphoma research related to the development, diagnosis and treatment of the disease in Vietnam veterans.

Lymphoma is the second fastest growing cancer by rate of incidence. It is estimated that approximately 87,200 Americans will be diagnosed with lymphoid malignancies in the year 2000 with a 50% mortality rate. We are currently making strides in the fight against cancer, as evidenced by the decline in some cancer rates. However, the State of California ranks number one in reported lymphoma cases in the nation. And yet, in the State of California where I have my residence, the State-funded Cancer Surveillance Program at the University of Southern California, does not have any data about cancer occurring in Vietnam veterans exposed to Agent Orange. This situation does not help our understanding of cancer and, in particular, the disabilities of those service men and women who fought for our country.

Please seriously consider our request as we try to assist those who must face the challenge of fighting for their lives once again, only this time, the enemy is a deadly cancer known as lymphoma.

Thank you very much for your attention to this important issue. I would be happy to answer any questions you may have.



Mr. HOBSON [presiding]. Steve, did you have anything to say?

Mr. HORN. I introduced her, and I think all of us would be moved by this testimony. We need to know that the VA does admit this and does have a way to deal with it, and that is one thing. But then the question is how many cases do we have to have before something else is done in a preventive sense.

Ms. DOUGLASS. Yes. We would like to see funding for research for solutions to the problem. I know that you are doing research and statistical data. But we are really looking for solutions because we know dioxin caused the lymphoma. So the researchers doctor can actually go after better solutions for treatment.

Mr. HOBSON. I think we all share your concern. I appreciate very much your coming in.

Ms. DOUGLASS. Thank you.

Mr. HOBSON. I have a number of friends who served in Vietnam. Steve and I are a little older than that. But I look at that, and I know my friend's age when he was there, I have seen his pictures, and he looks like almost the same age, a Marine in Vietnam.

Ms. DOUGLASS. Well, they are 40 and 50 years old, and they are dying. Councilman Schultz in the City of Long Beach, his friend, he just went to a funeral on Thursday to bury a friend who suddenly got sick and died from cancer-related illnesses.

Mr. HOBSON. I assure you we will take a look at this and see what we can do.

Ms. DOUGLASS. Thank you very much. You have brought a good advocate here too.

Ms. DOUGLASS. Yes.

Mr. HORN. We might think about cross-relations between the VA and NIH in some of this research. Because as you know, NIH has flexibility where they can assign a lot of the market.

Mr. HOBSON. Right. And we have put a lot of money into NIH.

Mr. HORN. Yeah, millions.

Ms. DOUGLASS. It was the lymphoma research experts with the Foundation last year that did not know the connection outside of the research doctors that do that research. They were not aware.

Mr. HORN. Thank you very much for your time.

Mr. HOBSON. Thank you very much for coming.

Ms. DOUGLASS. Thank you. Nice meeting you.

Mr. HOBSON. My pleasure.

THURSDAY, APRIL 13, 2000.

## NATIONAL COALITION FOR OSTEOPOROSIS AND RELATED BONE DISEASES

WITNESS

ARNOLD MOSES, M.D., DIRECTOR, METABOLIC BONE DISEASE CENTER AT THE STATE UNIVERSITY OF NEW YORK AT SYRACUSE

Mr. HOBSON. Sir, you are Arnold Moses?

Dr. MOSES. Correct.

Mr. HOBSON. Okay.

Dr. MOSES. On behalf of the National Coalition for Osteoporosis and Related Bone Diseases, the Bone Coalition, I would like to thank you for this opportunity to discuss briefly bone disease re-