

In order to prevent any further agency intransigence in promulgating regulations pursuant to the Departments' remaining rulemaking authority, the 1994 amendments contained a sunset provision which terminates the Departments' ability to issue regulations if they fail to do so within 18 months of the date of enactment. The Departments' rulemaking authority is set to expire on April 25, 1996.

Since enactment of the 1994 amendments, the tribes and the Departments have proceeded to negotiate a draft set of regulations to carry out the terms of the act. Although the tribes and the Departments finished work on the draft regulations by the end of October 1995, the two Government shutdowns and a spate of bad weather prevented the agencies from publishing the proposed regulations until January 24, 1996. The 60-day public comment period runs until March 25. The tribes and the Departments have both committed to a final meeting prior to publication of the final regulations in order to review, discuss, and reach a consensus regarding the comments received by the Departments.

The tribes and the Departments both fear that there will not be enough time to conduct a final meeting and allow for adequate agency review and integration of tribal comments into the final regulations by April 25. The tribes and agencies are in agreement that they are better off with the negotiated regulations than with no regulations at all. Thus, the tribes and the Departments have asked Congress to amend section 107(a)(2)(B) of the Indian Self-Determination Act to extend the sunset provision by 2 months.

Mr. Speaker, that is what this bill does. I would like to note that not only does this bill have the support of the Indian tribes and the administration, but it enjoys bipartisan support in the Congress. I urge my colleagues to support its swift passage.

THE RICKY RAY HEMOPHILIA RELIEF FUND ACT: HELPING THE VICTIMS OF HEMOPHILIA-ASSOCIATED AIDS

HON. GERRY E. STUDDS

OF MASSACHUSETTS

IN THE HOUSE OF REPRESENTATIVES

Wednesday, March 6, 1996

Mr. STUDDS. Mr. Speaker, I would ask each of my colleagues to imagine that you are the parent of three fine sons, each of whom has inherited the gene for hemophilia. Then imagine, if you can, that each of your sons acquires the AIDS virus through a contaminated blood transfusion. Your first son dies at age 40; the second, at 37, and your surviving son is very sick. Among them, they have nine children—your grandchildren—all of whom will be left fatherless.

At least one family in my congressional district does not have to imagine what that would be like. They know, because it is precisely what has happened to them. The heart-breaking story of the family of Joseph and Jacqueline Savoie is movingly told in an article by Liz Kowalczyk of the Patriot Ledger, published January 6-7, 1996, which I ask to have inserted in the RECORD.

Nor is their story unique. I have received letters from people throughout New England who have lost family members to hemophilia-asso-

ciated AIDS. At least 8,000 people with hemophilia and other blood-clotting disorders contracted HIV/AIDS from transfusions of contaminated antihemophilic factor [AHF] between 1980 and 1987. This means that as many as half of all individuals who suffer from blood-clotting disorders were exposed to HIV through the use of AHF.

Every death from AIDS is a tragedy that touches many lives. Yet who can fathom the sheer devastation inflicted on families such as these? The enormity of their experience becomes still more compelling when one learns that the Government could have acted to prevent it.

In 1980, when the first gay men began falling ill from the mysterious ailment that would ultimately be called AIDS, the technology became available to pasteurize blood-clotting agents. Yet for 7 years the Reagan administration failed to require the blood products industry to make use of this technology. Nor did the Government require the industry to inform the public about the risks of contamination with blood-borne pathogens such as HIV.

The failures of our public health system that contributed to this catastrophe are documented in a report by the Institute of Medicine of the National Academy of Sciences, commissioned by Secretary Shalala and published last year. The report recommends a series of steps that will help ensure the safety of the blood supply so that future tragedies can be prevented.

Such forward-looking measures are essential. But we also have a responsibility as a society to make restitution to those for whom these steps have come too late. That is why I have joined with Congressmen PORTER GOSS of Florida in introducing bipartisan legislation to provide partial compensation to these individuals and their families. The bill, H.R. 1023, is known as the Ricky Ray Hemophilia Relief Fund Act. It is named for a young man from Florida with hemophilia-associated AIDS, who died in 1992, at the age of 15.

The bill would establish a Federal trust fund to provide \$125,000 in compensation to victims or their survivors. This may seem like a substantial amount of money in these budget-cutting days. In fact, it will not even cover the annual medical costs incurred by many of these families. As Steve Savoie wrote to me last year, "I have been stripped of my dignity and can no longer support my family. * * * The financial stress is a big part of our lives. * * * There are days I can just barely make it through the day, only to get bill collectors calling the house looking for payment."

The compensation this legislation would provide cannot undo the terrible harm that has been done to Ricky Ray, Joe, Phil, and Steve Savoie, and the thousands like them. But it is the very least we can and must do. I commend Congressman GOSS for introducing this bill, and urge my colleagues to join us and our 181 current cosponsors in supporting it.

[From the Patriot Ledger, Jan. 6-7, 1996]

ANGER, TEARS REVEAL FAMILY'S TRAGEDY

(By Liz Kowalczyk)

For the past five years, Joseph and Jacqueline Savoie have watched life slip away from their three youngest sons. But they couldn't bring themselves to tell people why.

When the boys were born with hemophilia in the 1950s, the Savoies thought that was the worst they would have to face.

Each time Joseph Jr., Steven and Philip hurt themselves playing baseball or climbing

a tree, they were guaranteed a series of transfusions and weeks in the hospital.

So when drug companies started selling a blood-clotting solution that their sons could inject at home, the Savoies were thankful.

Then their gratitude turned to outrage.

The same product that granted Joe, Steve and Phil such freedom became a death sentence.

Sometime during the early to mid-1980's each of the three brothers contracted the AIDS virus from contaminated blood used in the clotting solution.

Joe was the first to die of AIDS-related lung cancer in January 1992. He was 40.

Phil, the baby of the family, died June 6 of AIDS-related illnesses, including pneumonia. He was one week short of his 38th birthday.

Steve, 41, is the sole survivor.

"I'm really scared," he said. "Since Thanksgiving, I've had problems with my throat. I'm afraid it's the beginning of things."

His weight has dropped from 200 to 176 pounds, and his tonsils have become so swollen in the last few days he just eats Cream of Wheat.

Steve's mother lies awake at night and prays.

"We prayed for a miracle, we prayed for drugs, we prayed to every saint, and finally you give up," she said. "You feel like you're sitting on railroad tracks and you know the train is coming but there is nothing you can do to stop it."

Kathy Savoie, Steve's wife, interjected: "We're still praying."

The Savoies told no one but a few close friends and their extended family what was killing their sons. Not their coworkers and not their neighbors in Weymouth and Abington. They worried that people in their suburban communities would ostracize them or ask too many painful questions.

But Steve convinced his family that talking about their very personal tragedy will help ease their frustration.

Steve and Kathy live in Weymouth with their two teenagers, Steven Jr., 14, and Kelly, 17. Kathy and the children have tested negative for HIV, the virus that causes AIDS.

He decided to tell his story after the Supreme Court declined in October to consider a class-action lawsuit, which was brought by AIDS-infected hemophiliacs against four drug companies and the National Hemophilia Foundation.

He and the rest of the family are also frustrated that legislation giving \$125,000 to anyone with hemophilia-related AIDS, or to their survivors, has been stalled in Congress for months. Supporters say the money would compensate victims for the Food and Drug Administration's failure to pull the contaminated products off the market sooner.

"It makes me so awful damn mad to think we lost two boys and they sit back and act like it's nothing," said Joseph Savoie, a retired Weymouth firefighter who now lives in Abington with his wife.

The Centers for Disease Control estimates that 10,000 hemophiliacs—half of all those in the United States—contracted the AIDS virus before the mid-1980s. That's when drug companies started heat-treating the blood products used in the clotting solution, a procedure that usually kills the virus.

About 2,000 hemophiliacs nation-wide have died of AIDS. In Massachusetts, 358 people are known to have contracted HIV from blood products. Two-thirds of those people have died. Activists estimate that in the suburbs south of Boston about two dozen families have children who are infected.

The numbers haunt Steve Savoie.

"The last time I was in the hospital, I was looking out the window," he said, "I imagined I saw Joe's and Phil's faces. They were

asking me to do something. I'm the only one left."

"WE WERE HELLIONS"

During the 1950s and 1960s, when Joe, Steve and Phil were children, hemophiliacs had to go to the hospital for blood-clotting transfusions.

Hemophiliacs—who are almost always boys who inherit the condition from their mothers—lack clotting proteins in their blood. Some needed weekly transfusions. Less severe hemophiliacs, like the Savoie brothers, have some clotting power in their blood, and need transfusions only when they get hurt.

"The doctors said not to climb trees, but we did. They said not to ice skate, but we did," he said. "We were hellions."

Steve ended up in the hospital every couple of months for the little accidents that almost every kid stumbles into. Once, he absentmindedly stuck his tongue to an iced-over porch railing and pulled off the skin. Another time, he tripped over some bricks in a yard while delivering newspapers. The sprained ankle caused internal bleeding.

So in 1968, when the FDA approved the first clotting powder that hemophiliacs could mix with sterile water and inject at home, it seemed like a gift.

But there was a problem. By the late 1970s, the clotting medicine was manufactured from the blood of tens of thousands of donors, many of them intravenous drug users who were paid for their blood.

The collection centers did not screen them for HIV, and just one infected donor could contaminate the entire pool of blood.

Steve said he had no idea how big a risk he was taking each time he injected the solution until one night in 1985 or 1986 when he turned on the national news.

He was shocked by what he heard: There was evidence that the blood products were contaminated with the AIDS virus, and hemophiliacs should order heat-treated blood products. Steve said he immediately called his brothers to warn them.

The next morning, Kathy Savoie called the New England Hemophilia Center at Worcester Memorial Hospital, from which the Savoies ordered their clotting medicine.

"They said we could not get a new supply until ours was gone," she said. "I hung up, we took everything out of the refrigerator and put it all in a big garbage bag. I called them back and said 'We're out of it, so send us the heat-treated stuff.'"

But it was too late.

Jacqueline Savoie said tests later showed that Joe, an electrician, was infected sometime in the spring of 1984. She's not sure when Phil, a carpenter, contracted the virus.

Steve was so afraid that he waited six months to get tested for HIV, and then he waited another six months to call for the results.

Steve said he doesn't know exactly when he was infected. AIDS first started appearing in the United States in 1981, and the drug companies did not start exclusively selling heat-treated blood products until 1985. His infection was probably sometime in between.

During that period, Steve worked as a carpenter, and as is often the case in his line of work, he was injured several times. He could have contracted the virus in July 1984, the month that he replaced the roof on his house. When the wooden planks he was standing on collapsed from their metal staging, he fell to the ground.

LIVING WITH ANGER

One day last month, Joseph, Jacqueline, Steve and Kathy gathered to talk around the kitchen table at the younger couple's home in Weymouth.

Joseph Savoie retired in 1983 after 30 years as a Weymouth firefighter, and built a house

in Abington. All of the couple's other children—Rhona Barone, David Savoie, Joann Dunbar and Dan Savoie—have stuck close to home, settling in either Weymouth or Abington. Another child, also named Joseph, died of meningitis as an infant many years.

But these days many of the family's traditionally boisterous birthday and Christmas parties end in tears, so they just don't get together as often. Joseph and Jacqueline have 27 grandchildren, four great-grandchildren and two more great-grandchildren on the way.

"I had everyone over for Christmas, and I tried to be strong," Steve said. "I didn't want to show my sadness. But it was a terrible night for me."

Steve is one of the quieter members of the family, and his parents and wife express many of the emotions one would expect him to show. He holds it in.

His wife is hopeful that he will live a long time. His father is sad, and his tears come easily. When his parents talk about the past 10 years, they both have have spurts of anger.

Everyone seems numb.

"There's no sudden impact," Joseph Savoie said. "It's not like you open the door and there it is. We live with each new pain, day to day."

What makes Joseph and Jacqueline so mad is that all three of their sons were born with mild cases of hemophilia, so mild that if they'd known about the risk of contracting AIDS, they would not have used the clotting product. They would have waited out the pain of an internal injury, or checked into a hospital for a transfusion, which would have greatly lessened the chance of HIV infection.

The more they've found out, the angrier they've become.

Steve said the drug companies should have been purifying their products with heat treatment long before AIDS became a problem. There was suspicion as early as the 1970s that hemophiliacs were contracting hepatitis from the blood products.

He said the National Hemophilia Foundation did not advise members against injecting the products in the early 1980s because it received financial support from the drug companies, Rhone-Poulenc Rorer; Armour Pharmaceutical; Miles, Baxter Healthcare; and Alpha Therapeutic.

The manufacturers have said they acted as quickly as possible, and that little was known about how AIDS was transmitted.

A recent report from the non-profit Institute of Medicine said the FDA depended too heavily on company officials for advice on whether to pull the products off the market.

And even after the companies started the heat treatments in 1983, the companies kept selling the old product for two years, according to Wendy Selig, assistant to Rep. Porter Goss, the Florida Republican who proposed the compensation legislation.

Today many AIDS-infected hemophiliacs are pursuing individual lawsuits. But in many states they are running into obstacles, such as a statute of limitations.

A few people are suing Worcester Memorial Hospital, and Dr. Peter Levine, the former medical director of the hemophilia clinic and now chief executive officer of the hospital. Levine declined to comment.

TOUGH TO KEEP GOING

Before he died, Phil Savoie served on the board of directors of the Committee of Ten Thousand, which spearheaded the class-action lawsuit against the drug companies.

Steve used to ignore his brother's pleas for help with his work.

"I was running from it," Steve said. "I used to take the documents he'd give me and just file them away. They made me too upset."

Today he wishes he had done more then, and could do more now. He would like people to pressure Congress to pass the compensation bill.

The family recently contacted one lawyer, but was told they might not be able to sue successfully because of the state's statute of limitations in such cases. The family plans to investigate this further.

And while Steve says he'd like to be more active in the fight for compensation, it's become harder to maintain his energy.

He stopped working as a carpenter three years ago when he came down with shingles. He remained fairly healthy until November, when he had to check into Quincy Hospital twice for bleeding in his esophagus. But mostly, he is just exhausted.

"I don't go out much anymore," he said. "There are a lot of lousy moments."

Steve and Kathy, an auto claims supervisor for a local insurance company, don't have the physical relationship they used to have. To feel close, they sit by a fire and talk. A good day is like the one they spent in Hyannis in October, visiting craft shops and stopping for lunch.

While Kathy is working, Steve does laundry and housework—if he feels well enough.

"He'd rather remodel the entire house than do laundry," Kathy said. The last few times he's felt energetic, Steve built rollers for the kitchen drawers and put down a new basement floor.

He gives Kathy pop quizzes about what to do if something goes wrong in the house.

"He's so afraid that I might not be able to keep things going," she said. "He's tried to pick out his funeral plot and I won't. I hate all the planning. I don't want to throw in the towel."

Sometimes they just sit and cry for hours.

Steve tries to spend as much time as he can with his children. He let them miss a day of school to go sledding. On Thanksgiving eve, he baked nine pumpkin, squash and mincemeat pies with the two teenagers, an effort that left him exhausted and in bed the next day.

"We tell them I'm feeling good and doing all the right things," he said. "We just have to enjoy our time together."

LEGISLATION INTRODUCED BY REPRESENTATIVE ED MARKEY ON BIOLOGICAL WEAPONS

HON. JOSEPH P. KENNEDY II

OF MASSACHUSETTS

IN THE HOUSE OF REPRESENTATIVES

Wednesday, March 6, 1996

Mr. KENNEDY of Massachusetts. Mr. Speaker, I rise in strong support of legislation introduced by Representatives MARKEY, KASICH, and myself addressing problems associated with biological and chemical weapons and the potential threat to the American public.

Together, we have developed two pieces of legislation: first, the measure deals with access to etiological agents, also commonly referred to as pathogens, toxins, or disease organisms, and second, a measure, which I will introduce in the very near future, deals with the appropriate criminal punishments when these agents are used as a weapon of mass destruction to cause death or inflict harm or damage.

JOHN KASICH, ED MARKEY, and I intend to offer amendments to the comprehensive antiterrorism legislation scheduled for consideration before the House of Representatives next week.