10,000 Hemophiliacs

Those who got HIV through bad blood are still trying to be compensated for government negligence. Doug Ireland finds that Clinton doesn't feel their pain.

December 1, 1999 By Doug Ireland

Ricky Ray was the oldest of three brothers with hemophilia who were infected by HIV-contaminated plasma in the early 1980s. These were the real Dark Ages for HIVers: In 1987, when authorities in their hometown of Arcadia, Florida discovered that the boys had AIDS, they were banned from school; a year later, after the Rays won a back-to-class federal court order, an arsonist burned down their school.

But Ricky would not be beaten. He became a national aids poster boy and peppered presidents Ronald Reagan and George Bush with letters urging them to boost AIDS funding and speak out about the epidemic. In 1992, when President-elect Bill Clinton--in full "I feel your pain" mode--found out that Ricky's letters had gone unanswered, he called Ricky as he lay dying in a hospital. Clinton pledged to do more for AIDS and invited Ricky to his inauguration.

Ricky, 15, died too soon to make it, and Clinton wrote to his family vowing that "his voice will be remembered." Once in office, Clinton presented a posthumous award to Ricky for his AIDS activism. He has said he keeps Ricky's picture on his desk.

In 1998, after years of lobbying by the hemophilia community, Congress unanimously passed--and Clinton signed--the Ricky Ray Hemophilia Relief Fund Act, to set up a $750 million fund to compensate those infected with contaminated blood. But this was only an authorization, not an appropriation of actual money. When Clinton sent his budget to Congress this year--the first chance he had to actually request funds for it--lo and behold, he didn't ask for a dime. Ricky had become just one more piece of roadkill in this hypocrisy-driven presidency.

In 1995, the National Academy of Sciences found that the feds had failed to properly regulate the plasma industry or inform patients of risks from blood products that infected some 10,000 hemophiliacs. As Therese MacNeill, a Massachusetts mother of two hemophiliacs with HIV (one has died), puts it, "AIDS was next to the lettuce in the refrigerator. We were using a product that was supposed to be a medicine but was really a killer." Now a spokesperson for the Committee of Ten Thousand (COTT), the organizaton of HIV positive hemophiliacs leading the fight for funds, she blames 'government negligence and corporate greed" by plasma suppliers such as Bayer, Baxter and Alpha, and says, "As a result, our kids have suffered for 18 years. Many of us haven't been

able to pay for funerals." This summer--when MacNeill led delegation to ask Sandra Thurman for help, the AIDS czar turned a cold shoulder, referring them to the Office of Management and Budget, which quarterbacks budget talks with Congress. No help from OMB, either.

The funds sought are embarassingly small: $750 million would provide a one-time-only payment of $100,000 to each victim (some 5,000 have already died), whereas it costs $160,000 a year to treat a hemophiliac with HIV. Asked about Clinton's failure to request this pittane, Sen. John Kerry, the Massachusetts Dem who has co-led the funding fight, told *POZ:* "It breaks faith in an unacceptable way. Half the hemophiliacs in America contracted AIDS in the '80s because of the faulty government-regulated blood supply. It's a national disgrace." Kerry, one of whose closest friends has hemophilia, calls full funding "a simple matter of justice."

Fortunately, COTT also has allies among Republican members of appropriations committees, including Floria Rep. Porter Goss and Ohio Sen. Mike DeWine. Facing budget caps, other lawmakers claim their hands are tied. But as MacNeill observes, "They find ways to get around the caps for everything from Columbine to Kosovo to tornadoes." Clinton's failure to ask for money has pitted the Ricky Ray Act against other needy programs in the end-of-session spending scramble. Absent any push from the White House, congressional leaders may compromise away part or all of the Ricky Ray money.

Some 6,000 applications for Ricky Ray funds are already filed. Says COTT lobbyist Dave Cavanaugh, "The demand is not so far about 50 percent of those infected, it makes sense to fully fund the program now, so the families can collect these long-over-due payments and find some peace."

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