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S.P. v. SULLIVAN: THE EFFORT TO BROADEN THE SOCIAL SECURITY ADMINISTRATION'S DEFINITION OF AIDS

*Theresa M. McGovern**

I. Introduction

M.C.,¹ a Latina residing in East Harlem and suffering from Human Immunodeficiency Virus (HIV), has had intractable gynecological illnesses since 1984. M.C.'s illnesses have caused seven hospitalizations for pelvic inflammatory disease, four hospitalizations for cervical and/or ovarian carcinoma and two hospitalizations for pneumonia. She has also suffered persistent aggressive yeast infections, urinary tract infections, diarrhea and vomiting. Yet, when she applied for Supplemental Security Income benefits in 1985, her application was denied. In July, 1988, her request for reconsideration was also denied.

In denying her requests, the Social Security Administration (SSA) based its decisions on the Center for Disease Control's (CDC) definition of Acquired Immune Deficiency Syndrome (AIDS). The CDC's definition was predicated on its surveillance of the disease as it developed in white gay males. The definition was not intended to define the characteristics required to obtain benefits. Most disconcerting to M.C., and a central concern of this Essay, was that the CDC's limited definition did not include her symptoms. M.C. did not receive a favorable determination on her claim until April 4, 1991, six years after her initial application.

M.C. was not the only HIV-positive person whose Supplemental Security Income benefits were delayed. Many women, and men suffering from diseases other than those typically experienced by the white gay males surveyed by the CDC when it defined AIDS, were also denied benefits. This Essay describes how the activism of the HIV Law Project and other organizations and individuals forced the Social Security Administration to consider additional

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1. The names of the plaintiffs have been abbreviated to protect their privacy.

symptoms when deciding whether to award benefits for people living with HIV.

Part II of this Essay introduces *S.P. v. Sullivan*,² the leading case on expanding the working definition of AIDS. It also includes a history of the CDC surveillance definition and a description of the SSA's use of the CDC's surveillance definition of AIDS. Part III discusses the *S.P. v. Sullivan* litigation, including a brief overview of one of the individual cases brought by the nineteen plaintiffs participating in the litigation. Part III also analyzes the evolution of the definitive Listing promulgated by the SSA, which is a short-cut blueprint for qualifying for the Disability Insurance Benefits program and the Supplemental Security Income (SSI) program. Part IV describes the political activism by the HIV Law Project and others that led to the adoption of a new HIV Listing. Finally, Part V is a postscript about one of the plaintiffs.

II. Background to the Case

On October 1, 1990, eleven men, women and children filed a class action lawsuit against Louis W. Sullivan, M.D., the Secretary of the United States Department of Health and Human Services (HHS).³ The plaintiffs were severely disabled by HIV, yet adjudged "able to work" by the SSA. In December, 1991, eight more individuals intervened in the lawsuit.⁴ The plaintiffs claimed that the problem with the CDC surveillance definition was that it was developed as a tool to survey the trends in AIDS, rather than as a method for awarding disability benefits for HIV-related conditions.⁵

2. Third Amended Class Action Complaint, 90 Civ. 6294 (S.D.N.Y. filed Dec. 7, 1991).

3. *Sullivan*, 90 Civ. 6294 (S.D.N.Y.) The plaintiffs were represented by the author, who was lead counsel; Jill A. Boskey of MFY Legal Services; Leslie Salzman and Toby Golick of Cardozo Bet Tzedek Legal Services; Mary Gundrum of the Center for Constitutional Rights and Sandra Lowe, Marian Rosenberg, Michael Isbell and Suzanne Goldberg of Lambda Legal Defense and Education Fund.

4. These individuals were represented by Nancy Chang, Lauren Shapiro and Johnson Tyler of Brooklyn Legal Services, Corporation B.

5. *Sullivan*, 90 Civ. 6294 at ¶¶ 41, 57-59.

A. The SSA's Use of the CDC's Surveillance Definition of AIDS

The SSA administers the Disability Insurance Benefits program⁶ and the Supplemental Security Income (SSI) program.⁷ These programs provide monthly cash benefits to persons who are unable to work because of a physical or mental impairment, or combination of impairments, that can be expected to result in death or have a duration of at least one year.⁸

Regardless of the nature of the impairment, the Secretary of the SSA has established a five-step sequential evaluation procedure for determining whether a person is disabled and thus eligible for SSI benefits.⁹ This five-step evaluation can be divided into essentially two tiers. The first tier of this evaluation dictates that if a claimant is not currently working (step one) and has a severe impairment (step two), that person will be awarded benefits if his or her impairment is catalogued on the SSA's listing of impairments (Listing) (step three).¹⁰ If a person's impairment is on the Listing, he or she automatically qualifies for benefits.¹¹ Thus, the Listing serves as a short-cut method for qualifying for benefits. Seventy-five percent of the people found eligible for disability benefits are found eligible through this procedure.¹²

If, however, an applicant does not have an impairment enumerated in the Listing, the applicant must satisfy the second tier of the SSI evaluation to qualify for benefits. The claimant must establish that he or she lacks the residual functional capacity to meet the physical and mental demands of his or her prior work (step four) and, in light of the person's age, education and vocational background, cannot perform any other substantial, gainful activity (step five).¹³ If a claimant is initially denied benefits or is refused at any stage of the provided four levels of administrative review,¹⁴ he or

6. 42 U.S.C. §§ 401a-401m (1993).

7. 42 U.S.C. §§ 1382a-1382j (1993).

8. 42 U.S.C. §§ 423 (d)(1)(A), (2)(A) (1990); 42 U.S.C. §§ 1382 c(a)(3)(A), (B) (1993).

9. Evaluation of Disability, 20 C.F.R. § 404.1520 (1993); Evaluation of Disability, 20 C.F.R. § 416.920 (1993).

10. 20 C.F.R. § 404.1520; 20 C.F.R. § 416.920; Listing of Impairments, 20 C.F.R. subpt. P, app. 1, § 404 (1993).

11. 20 C.F.R. § 404.1520 (a); 20 C.F.R. § 416.920 (d).

12. *Wilkerson v. Sullivan*, 904 F.2d 826, 839 (3rd Cir. 1990).

13. 20 C.F.R. §§ 404.1520 (a); 20 C.F.R. §§ 416.920 (a).

14. In New York State, the four levels of review are 1) initial determination by the Office of Disability Determination; 2) reconsideration by the Office of Disability Determination; 3) administrative hearing before an administrative law judge; and 4) re-

she has sixty days to file an appeal of the decision with the SSA. If a claimant is denied at *all* four levels of review, he or she can file an appeal in a federal district court.¹⁵

The SSI's Listings are published in the *Code of Federal Regulations* and are submitted to the public for notice and comment upon publication. Until July, 1993, however, the SSA had never promulgated a Listing governing HIV-related disabilities.¹⁶ Instead, the state SSA depended upon such sources as Rulings promulgated by the federal SSA, which, in turn, relied heavily upon the CDC definition in outlining eligibility criteria. Until 1993, the only regulation promulgated by the Secretary of the SSA regarding AIDS was a presumptive disability regulation published in 1985. This regulation enabled those with CDC-defined AIDS to qualify for presumptive disability benefits while they waited for a decision on their applications.¹⁷ In 1988, in response to public criticism regarding the SSA's reliance on the CDC definition of AIDS when determining eligibility for benefits, the SSA acknowledged that the "CDC defines AIDS for public health and other purposes that are not necessarily intended to have prognostic significance nor to designate the severity of the illness."¹⁸

The plaintiffs in *S.P. v. Sullivan*¹⁹ centered their arguments on the insufficiency of the CDC surveillance definition as a basis for the award of disability benefits. Therefore, a history of the development of the CDC definition of AIDS is essential to grasping its inadequacy as a standard for awarding benefits.

B. History of the CDC Surveillance Definition

The CDC first became interested in AIDS in the early 1980s. In 1981, after early reports of *Pneumocystis carinii* pneumonia, Kaposi's sarcoma and other opportunistic infections in young gay men in San Francisco, New York and Los Angeles, the CDC began surveillance for a newly-recognized constellation of diseases called AIDS.²⁰ The CDC developed a surveillance-based definition for

view before the Social Security Administration's Appeals Council. Introduction, Definition, and Initial Determination, 20 C.F.R. § 404.900 (1993).

15. 20 C.F.R. § 404.900 (5).

16. 20 C.F.R. pt. 404, subpt. P, app. 1.

17. 20 C.F.R. §§ 416.931-416.934.

18. 53 FED. REG. 3739-01 (1988).

19. Third Amended Class Action Complaint, No. 90 Civ. 6294 (S.D.N.Y. filed Dec. 7, 1991).

20. CENTER FOR DISEASE CONTROL AND PREVENTION, REPORTS ON HIV/AIDS 1992 1 (August 1993).

this syndrome, and initially received case reports directly from health care providers and state and local health departments.²¹

The case definition of AIDS was expanded in 1985 and again in 1987.²² In 1987, the addition of extrapulmonary tuberculosis, wasting syndrome and encephalopathy resulted in a 25% increase in reported AIDS cases.²³ These cases occurred primarily among heterosexual African-American and Latino individuals. These new cases also included high numbers of intravenous drug users.²⁴

The CDC's narrow focus on young gay men resulted in the exclusion of illnesses already in existence prior to the advent of HIV, but exacerbated in a person infected with HIV. In other words, when defining AIDS, the CDC had entirely overlooked the possibility of converging epidemics.²⁵ For instance, by October, 1990, there were numerous studies linking HIV-infection with higher mortality and morbidity rates in persons with pulmonary tuberculosis²⁶ and bacterial pneumonia,²⁷ two diseases existing before the

21. As HIV was identified as the etiologic agent of AIDS, and the epidemic became more widespread, state and local health departments assumed responsibility for AIDS surveillance. By 1985, all states and local governments required health care providers to report AIDS cases directly to the state or local health department. Since then, these entities have been reporting to the CDC, which compiles national surveillance data.

22. *Revision of CDC Case Definition of Acquired Immunodeficiency Syndrome for National Reporting*, 34 MORBIDITY & MORTALITY WKLY. REP. 373-75 (June 28, 1985); *Revision of CDC Definition of Acquired Immunodeficiency Syndrome*, 36 MORBIDITY & MORTALITY WKLY. REP. S1-15 (Supp. 1, Aug. 14, 1987).

23. U.S. DEPT. OF HEALTH AND HUMAN SERVICES, *AIDS Public Information Data Set*, PUBLIC HEALTH SERVICE, CENTERS FOR DISEASE CONTROL, NATIONAL CENTER FOR INFECTIOUS DISEASES, DIVISION OF HIV/AIDS (1993).

24. *See id.*

25. *See id.* Women have always experienced gynecological disease and infection. Women who are HIV-positive gradually lose their ability to fight off infection. Thus, gynecological infections for these women are both more likely and more severe. Additionally, financially disadvantaged, HIV-positive individuals may suffer bouts of tuberculosis that are more severe. New strains of tuberculosis have been discovered among these individuals. *See* Susan Y. Chu, Ph.D., et al., *Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age*, 264 JAMA 225-29 (1990); C.L. Daley, M.D., et al., *An Outbreak of Tuberculosis with Accelerated Progression Among Persons Infected with the Human Immunodeficiency Virus*, 326 NEW ENGL. J. MED. 231-35 (1992).

26. *See, e.g.,* Karen M. Farizo, M.D., et al., *Spectrum of Disease in Persons With Human Immunodeficiency Virus Infection in the United States*, 267 JAMA 1798-1805 (1992); M. Miles Braun, M.D., et al., *Trends in Death with Tuberculosis During the AIDS Era*, 269 JAMA 2865-2868 (1993); Lawrence O. Gostin, J.D., *Controlling the Resurgent Tuberculosis Epidemic; A 50-State Survey of TB Statutes and Proposals for Reform*, 269 JAMA 255-61 (1993); C.L. Daley, M.D., et al., *An Outbreak of Tuberculosis with Accelerated Progression Among Persons Infected with the Human Immunodeficiency Virus*, 326 NEW ENGL. J. MED. 231-35 (1992); M. Miles Braun, M.D., et

advent of HIV. In addition, these studies also indicated that HIV-infected women incurred a greater risk for a more aggressive form of cervical disease²⁸ and a spectrum of gynecological and/or sexually transmitted diseases, including *inter alia*, pelvic inflammatory disease.²⁹

Moreover, clinical and epidemiological studies relating to HIV-related disease in New York City highlighted the inability of AIDS surveillance to capture HIV-related morbidity and mortality.³⁰ For example, between 25% and 40% of patients treated for HIV-related diseases on an in-patient basis in New York City hospitals were not included in the CDC definition of AIDS.³¹ Furthermore, in a two-year study of HIV-infected individuals in which 81% of the participants died, only 29% developed an illness meeting the CDC definition of AIDS.³² Over half (52%) died of infectious diseases like pneumonia, which are not recognized in the CDC definition of AIDS. These numbers demonstrate the gross inadequacy of the CDC definition.

III. The Litigation

The plaintiffs in *S.P. v. Sullivan* claimed that the SSA's standards and practices for evaluating the claims of persons alleging HIV-

al., *Increasing Incidence of Tuberculosis in a Prison Inmate Population: Association with HIV Infection*, 261 JAMA 393-97 (1989).

27. See, e.g., R.L. Stoneburner, M.D., et al., *Increase in Pneumonia Mortality Among Young Adults and the HIV Epidemic — New York City, United States*, 260 JAMA 2181, 2185 (1988); Karen M. Farizo, M.D., et al., *Spectrum of Disease in Persons with Human Immunodeficiency Virus Infection in the United States*, 267 JAMA 1798-1805 (1992).

28. See, e.g., Susan Y. Chu, Ph.D., et al., *Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age*, 264 JAMA 225-29 (1990); M. Maiman, M.D., et al., *Risk for Cervical Disease in HIV-Infected Women — New York City*, 265 JAMA 23-24 (1991); M. Maiman, M.D., et al., *Prevalence of Human Immunodeficiency Virus in a Colposcopy Clinic*, 260 JAMA 2214-15 (1988); Howard L. Minkoff, M.D., *Care of Women Infected with the Human Immunodeficiency Virus*, 266 JAMA 2253-58 (1991).

29. See, e.g., Constance B. Wofsy, M.D., et al., *Human Immunodeficiency Virus Infection in Women*, 257 JAMA 2074-76 (1987); David A. Grimes, M.D., *Deaths due to Sexually Transmitted Diseases; The Forgotten Component of Reproductive Mortality*, 255 JAMA 1727-29 (1986); A. Eugene Wahington, M.D., M.S., et al., *Preventing Pelvic Inflammatory Disease*, 266 JAMA 2574-80 (1991).

30. See, e.g., *Current Trends in Mortality Attributable to HIV Infection/AIDS — United States, 1981-1990*, 127 ARCH DERMATOL 621-22 (1991).

31. *Sullivan*, 90 Civ. 6294, at 11, citing NEW YORK CITY DEPARTMENT OF HEALTH, *AIDS Case Projections, 1989-1993*, March, 1989.

32. *Id.* at 12, citing Chiasson, et al., *Clinical and Epidemiological Characteristics of Non-AIDS HIV-Related Illness in New York City Hospitals*, THIRD INTERNATIONAL CONFERENCE ON AIDS, Washington, D.C. (1987).

related disability³³ were arbitrary, capricious and contrary to the mandates of the Social Security Act. The plaintiffs argued that these standards and practices violated the Due Process Clause of the Fifth Amendment to the United States Constitution.³⁴

The plaintiffs also alleged that the challenged standards violated the Equal Protection guarantee of the Fifth Amendment because the definition of HIV-related disability excluded HIV-related manifestations that occurred only among women. For example, while HIV-infected women suffer from pelvic inflammatory disease, chronic genital ulcers and recurrent herpes, these disorders were not included in the standards the SSA had implemented. According to the plaintiffs, the root of the alleged discrimination was the SSA's inappropriate reliance on the CDC's surveillance definition of AIDS for purposes of evaluating claims and determining eligibility for HIV-related disability awards.³⁵ The plaintiffs argued that the CDC had developed an unfairly narrow list of indicator symptoms for AIDS by focusing its research primarily on white gay men, to the exclusion and hardship of other groups.³⁶

Further, the SSA had never published in the *Federal Register* the challenged standards and practices for notice and comment.³⁷ Based on this omission, the plaintiffs argued that the SSA had violated the Administrative Procedure Act, which requires federal agencies to make such information available to the public.³⁸

A. The Plaintiffs.

Of the nineteen plaintiffs in the litigation, all but one were found to have been disabled as of their application dates.³⁹ All of the

33. See *supra* Section II.

34. Social Security Act, 42 U.S.C. §§ 401, 402, 403, 404, 405 and 42 U.S.C. §§ 1381, 1381(a), 1382, 1382(a), 1382(b), 1382(c), 1382(d), 1382(e), 1382(f), 1382(g), 1382(h), 1382(i), 1382(j), 1383 (1988), and the implementing regulations, 20 C.F.R. pts. 404 and 416.

35. *Sullivan*, 90 Civ. 6294 at ¶¶ 35-77.

36. *Sullivan*, 90 Civ. 6294 at ¶¶ 1-30. The CDC has also admitted that its list of indicator diseases was restricted only to illnesses, such as Kaposi's sarcoma and toxoplasmosis, that rarely or never occur in the absence of HIV-infection. See *Revision of CDC Case Definition of Acquired Immunodeficiency Syndrome for National Reporting*, 34 MORBIDITY & MORTALITY WKLY REP. 373-75 (June 28, 1985); *Revision of CDC Case Definition of Acquired Immunodeficiency Syndrome*, 36 MORBIDITY & MORTALITY WKLY REP., S3-15 (Supp. 1, Aug. 14, 1987).

37. See *supra* notes 12-13 and accompanying text.

38. Administrative Procedure Act, 5 U.S.C. §§ 551-52 (1976); Federal Register Act, 44 U.S.C. § 1505 (1968).

39. The one plaintiff whose onset date is in dispute is currently appealing that denial.

plaintiffs, however, experienced delays in receiving benefits ranging from one to five years. In addition to M.C.'s situation described in the Introduction,⁴⁰ the following illustration provides direct evidence of the SSA's failure to recognize disabling HIV-related impairments not included in its AIDS definition.

At the time of filing for disability benefits, S.P. was a twenty-one year old Latina residing on the Lower East Side of Manhattan. In January, 1989, S.P. tested positive for HIV. In August of that same year, S.P. applied for SSI benefits because she was experiencing increasingly painful bouts of pelvic inflammatory disease, weight loss, headaches, shortness of breath and vomiting. Medical records confirmed not only the existence of these conditions, but they also indicated chronic pelvic pain, constant burning in the uterus and vagina, recurring fever and nausea, and an ovarian cyst. S.P. also submitted medical reports that indicated she also suffered from severe anemia, cervical lesions and a T-cell count in the 200-300 range.⁴¹ Furthermore, her treating physician noted that S.P. was unable to work whenever she experienced the pelvic and abdominal pain resulting from chronic pelvic inflammatory disease. Notwithstanding intermittent hospitalizations on account of these conditions, the SSA classified S.P. as HIV-positive but asymptomatic. The SSA therefore denied S.P.'s SSI claim at the initial and reconsideration stages.⁴²

S.P. appealed this decision. At the SSI hearing, S.P. testified that she had lost at least 10% of her body weight, that she suffered from chronic abdominal and pelvic pain, nausea and dizziness, and that she could not walk, sit or stand for long periods of time. The Administrative Law Judge (ALJ), however, denied her claim, finding that her allegations of disabling pain lacked credibility.⁴³ S.P. appealed the denial of benefits to the Appeals Council. The Appeals Council remanded the case to the ALJ to resolve the inconsistency

40. See *supra* note 1 and accompanying text.

41. See *infra* notes 53-57, 59 and accompanying text. It is widely believed in the medical community that AIDS is due to a depletion of T-lymphocytes bearing the CD4 receptor, known colloquially as T-cells. *Guidelines for the Performance of CD4 + T-Cell Determinations in Persons with Human Immunodeficiency Virus Infection*, 41 MORBIDITY & MORTALITY WKLY REP. 1-17 (May 8, 1992).

42. See *supra* notes 5-9 and accompanying text.

43. *Sullivan*, 90 Civ. 6294 at ¶ 87. In another case, the ALJ, ignoring a stunning list of disabling impairments, stated at the hearing that "until we have a full-blown case of AIDS on our hands . . . this is not a disabling impairment." *Id.* at ¶ 115. In yet another case, the medical advisor from the SSA testified that the claimant's pneumonia and endocarditis were not HIV-related and that her symptoms were caused by depression. *Id.* at ¶ 107.

between the medical evidence and the ALJ's findings.⁴⁴ At the next hearing the ALJ found S.P. to be disabled as of the date of her application. This favorable decision, which was granted more than two years after S.P.'s initial application, was based upon the same evidence that existed at the time of application.

B. The Litigation Continued and the Proposed Listing

Although the Department of Justice moved to dismiss the class action three times, alleging that the plaintiffs had failed to state an actionable claim, Judge Miriam G. Cedarbaum sustained the complaint, holding that the claimants had alleged factual issues that merited further explanation.⁴⁵

During the discovery stage, progress was made. The Secretary published interim regulations that constituted a Listing for HIV-related disabilities in December, 1991.⁴⁶ Unfortunately, this proposed Listing held to a higher standard those individuals who were suffering from severe HIV-related conditions that were not included in the AIDS definition. In addition, the Listing also excluded most infections specific to women.⁴⁷ Therefore, similar to the former standards, the proposed regulations discriminated against women and other groups not adequately studied by the CDC.

As a result, a functional test was applied to cases of persons suffering from severe conditions not included in the AIDS definition, such as bacterial pneumonia, pulmonary tuberculosis and endocarditis. These people had to prove that the impairment was "persistent and/or resistant to treatment," and that they met two of four conditions of an extremely stringent functional test. The first prong of the functional test required a "marked" inability to perform activities necessary for normal daily living. "Marked" was defined as *most of the time*.⁴⁸ The second prong of the functional test required a marked impairment of social functioning. The third prong required a marked inability to sustain concentration, persistence or pace. Finally, the fourth prong required repeated episodes of deterioration or decompensation in work or work-like settings lasting two or more weeks and occurring at least three times a

44. *Id.* at 25.

45. *Sullivan*, 90 Civ. 6294 (S.D.N.Y. June 7, 1991) (Cedarbaum, J. dismissing the government's motion).

46. 56 FED. REG. 65,702 (1991).

47. Pelvic inflammatory disease, chronic genital ulcers and recurrent herpes simplex were omitted. *Id.*

48. *Id.*

year.⁴⁹ After evaluating medical evidence, if two of these conditions were met, the patient would be eligible for SSI benefits.

IV. Activism

A. The Movement to Expand the AIDS Definition

Over three thousand sets of comments were filed with the SSA criticizing the proposed Listing. On April 2, 1992, the Subcommittee on Social Security and the Subcommittee on Human Resources of the Committee on Ways and Means held a hearing to review the proposed Listing. At the hearing, HIV-positive women, the American Medical Association, the Physician's Association for AIDS Care, the State of New York, the American Academy of Pediatrics, the National Association of People with AIDS and others criticized the stringency and overall imbalance of the proposed regulation.⁵⁰ The hearing was successful; after years of trying to force the CDC to expand the surveillance definition of AIDS, the efforts of physicians, activists and HIV-positive women helped establish the discriminatory nature of the Social Security Administration's criteria for awarding HIV-related disability benefits.⁵¹

Following the hearing, the CDC was forced to consider expanding the AIDS surveillance definition to address the widely noted undercounting of certain HIV-positive populations, including women, intravenous drug users and communities of color. The CDC considered addressing this problem by merely including only those HIV-positive individuals with a low white blood cell count.⁵² The CDC argued that this change would enable it to capture all those HIV-positive individuals who were severely immunocompromised, but who were not suffering from one of the twenty-three opportunistic infections listed in the 1987 surveillance

49. 56 FED. REG. 65, 702 (1991).

50. See *Obstacles that Prevent Women and Children with HIV-Related Disabilities From Qualifying For Social Security Disability Insurance and Supplemental Security Income: Hearing Before the Subcomm. on Social Security and the Subcomm. on Human Resources of the House Comm. on Ways and Means, 102nd Cong., 2nd Sess. 102-99 (1992).*

51. Katrina Haslip, an activist who died on December 2, 1992, worked tirelessly to force the CDC to recognize HIV-related illness in women. Unfortunately, at the time of Katrina's death on account of bacterial pneumonia, she did not meet the 1987 definition of AIDS. Had she lived one more month, Katrina would have qualified as an "AIDS death" because at that time bacterial pneumonia was added to the definition. This addition was due in large part to Katrina's work. For more information concerning HIV-positive women's involvement in this movement, see GENA COREA, *THE INVISIBLE EPIDEMIC* (1993).

52. See *supra* text accompanying note 52.

definition.⁵³ "Immunocompromise," or immune system damage, is predicted by the medical community through a white blood cell called the CD4 cell.⁵⁴ In general, to have less than two hundred CD4 cells is considered dangerous.⁵⁵ There has been much debate about the reliability of the test developed to determine the number of CD4 cells in an individual. Its ability to predict the onset of serious disease is questionable, since some HIV-positive people with less than two hundred CD4 cells can be relatively healthy and some HIV-positive people with more than two hundred CD4 cells can become seriously ill.⁵⁶ The CDC's proposed change would include in its definition only people whose CD4 count was two hundred or less.

Many HIV-positive individuals, activists and health care providers were dissatisfied with this proposal.⁵⁷ They argued that abandoning a disease-based approach in favor of a CD4-based approach would place too much reliance on the accuracy and availability of CD4 testing. In particular, advocates for women argued that the addition of only those with evidence of severe immunocompromise would not address the medical community's historic failure to diagnose HIV-related illnesses in women. For example, a woman with bacterial pneumonia or cervical cancer may never be tested for HIV, and without the evidence of HIV-infection, a CD4 test might never be administered. Thus, HIV-positive women would continue to be undercounted and underdiagnosed in the AIDS epidemic.

B. The New HIV Listing

Using the medical evidence collected for the Social Security litigation, the HIV Law Project convened a meeting early in the summer of 1992. The meeting was held to propose a targeted campaign to force the CDC to add three additional conditions to the definition of AIDS, which would qualify more HIV-positive victims for

53. *Revision of the CDC Case Definition for Acquired Immunodeficiency Syndrome*, 36 MORBIDITY AND MORTALITY WKLY. REP. (June 28, 1985).

54. *1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults*, 41 MORBIDITY AND MORTALITY WKLY. REP. 1, 1-2 (Dec. 18, 1992). See *supra* note 42 and accompanying text.

55. See generally PAUL ALBERT, ET. AL., AIDS PRACTICE MANUAL (3d ed. 1992).

56. *Id.*

57. The HIV Law Project was involved in a collaborative effort, which was called "The CDC Consensus Coalition," in order to voice concerns about this proposal. Nationwide, hundreds of people signed the consensus statement on the inadequacies of the 1987 definition.

government benefits. The HIV Law Project chose physical conditions that had the most medical evidence of recurrence and a more rapid advancement in the presence of HIV infection. The three conditions were cervical cancer, recurrent bacterial pneumonia and pulmonary tuberculosis.

Working with ACT UP, New Jersey Women AIDS Network, the ACLU and a coalition of local and national HIV organizations, the HIV Law Project developed a proposal that demanded the addition of these three conditions, as well as the guaranteed confidentiality of all CD4 testing.⁵⁸ Over three thousand individuals and organizations supported the proposal. In June, 1992, at a plenary session at the International AIDS Conference in Amsterdam, the HIV Law Project presented it to the CDC.

That fall, the CDC hosted a meeting of HIV-positive women, activists, physicians and advocates to discuss the proposal. There was widespread agreement that the proposal was a good way to begin redressing many of the deficiencies of the 1987 surveillance definition.⁵⁹

In November, 1993, the CDC announced that it was expanding the surveillance definition, effective January 1, 1994, to include the three conditions from the community proposal. This newly expanded definition also includes any HIV-positive individual with a CD4 count of two hundred or less.⁶⁰

On July 2, 1993, the SSA established a new and final Listing for the evaluation of HIV infection.⁶¹ This Listing actually includes conditions common to women.⁶² The new Listing also adds numerous serious illnesses without requiring a claimant to meet the strin-

58. THE HIV LAW PROJECT, COMMUNITY PROPOSAL TO EXPAND THE AIDS DEFINITION (1992) (on file with author).

59. See *supra* text accompanying note 52.

60. See *supra* note 55 at 1-17.

61. This new Listing represents a victory for the plaintiffs in the class-action lawsuit, *Sullivan*, 90 Civ. 6294 (S.D.N.Y.). The Listing also responds to H.R. 2299, a bill filed by Representative Robert Matsui (D-Calif.), which also sought to force the SSA to award benefits to all those disabled by HIV diseases.

62. Among the conditions are multiple or recurrent bacterial infection, including pelvic inflammatory disease, which requires hospitalization or intravenous antibiotic treatment three or more times in one year. These conditions also include conditions of the skin or mucous membranes with extensive fungating or ulcerating lesions not responding to treatment, including dermatological conditions such as eczema or psoriasis, vulvovaginal or other mucosal candida, condyloma, caused by human papilloma virus, genital ulcerative disease and invasive cervical cancer. 58 FED. REG. 36,008 (1993).

gent functional test.⁶³ In addition, the Listing contains a new catch-all section, which should enable anyone with a serious HIV-related condition that results in documented symptoms to qualify.⁶⁴

Presently, the parties in *S.P. v. Sullivan* are in settlement negotiations to determine the extent of retroactive benefits to be awarded to the plaintiffs.

V. After the Victory

Sadly, S.P., the lead plaintiff in the class action lawsuit, died in January, 1994. Only two months prior to her death, the HIV Law Project represented her at a termination of parental rights proceeding involving her oldest daughter. Part of the agency's case was based upon S.P.'s failure to effectuate financial stability and an appropriate home in which to reunite the family. Part of S.P.'s defense was that her SSI benefits had been won only after several years of major litigation. Since she was dying at the time of the final hearing date in the termination proceeding, the HIV Law Project was able to get the city to withdraw the proceeding. S.P., how-

63. See *supra* Section 2B. See also 58 FED. REG. 36,008 (1993). The List adds one or more of the following infections resistant to treatment or requiring hospitalization or intravenous treatment three or more times in one year: Sepsis, Meningitis, Pneumonia, Septic arthritis Endocarditis, Radiographically documented sinusitis, Pulmonary tuberculosis resistant to treatment—resistant to treatment means that a condition did not respond adequately to an appropriate course of treatment, Disseminated infection—disseminated means that a condition is spread widely over a considerable area or body systems, Herpes zoster (either disseminated or with multidermatomal eruptions that are resistant to treatment), Kaposi's sarcoma (with extensive oral lesions, or involvement of the gastrointestinal tract, lungs or other visceral organs, or involvement of the skin or other mucous membranes), Anemia, Granulocytopenia, Thrombocytopenia, Neurological manifestations of HIV infection (e.g., peripheral neuropathy), HIV Wasting Syndrome (characterized by involuntary weight loss and, in the absence of a concurrent illness that could explain the findings, either: chronic diarrhea with two or more loose stools daily lasting more than one month or longer or chronic weakness and documented fever greater than 38 C (100.4 F) for the majority of one month or longer), and Diarrhea (lasting for one month or longer, resistant to treatment and requiring intravenous hydration, intravenous alimentation or tube feeding).

64. Previously, classification as repeated manifestations of HIV infection, or other manifestations, required evidence of oral hairy leukoplakia, which results in significant documented signs or symptoms (e.g., fatigue, fever, malaise, weight loss, pain, night sweats), and one of the following at the marked level:

1. Restriction of activities of daily living;
2. Difficulties in maintaining social functioning; or
3. Difficulties in completing tasks in a timely manner due to deficiencies in concentration, persistence or pace. Importantly, the marked level has been re-defined in response to severe criticism. It is defined as more than moderate and less than extreme, and no longer requires that the claimant be unable to function "most of the time." 58 FED. REG. 36,008, 36,020 (1993).

ever, was never reunited with her children. The SSA's, as well as the CDC's, failure to include S.P.'s illnesses in its definition of AIDS cost S.P. not only her benefits but also contact with her daughter. Hopefully, under the new Listing that was passed through the efforts of HIV-positive women and men, as well as AIDS activists, such a tragedy will not be repeated.