

It Takes Time...

Dec. 1924
First US gay rights
group founded —
Chicago Society for
Human Rights

1951
Mattachine Society
founded

1955
First US lesbian organ-
ization founded —
Daughters of Bilitis

June 27, 1969
Gay people riot at
Stonewall Bar in NYC,
igniting the gay libera-
tion movement

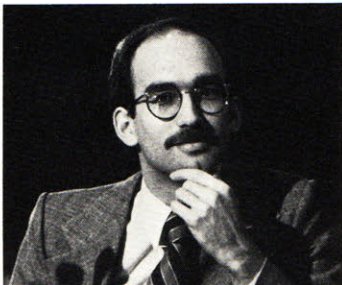
1970
Gay Liberation Front
founded

Nov. 15, 1973
NGTF founded by gay
& lesbian activists

Lobbying

The Task Force is the gay & lesbian community's lobby at the federal level. Whether securing protection from insurance discrimination, fighting for immigration reform or obtaining endorsements for gay civil rights from politicians and professional groups, the Task Force works every day to influence the decisions that shape gay lives. In addition NGLTF advances and safeguards gay interests with corporations, unions, professional and religious groups, and a wide range of political organizations.

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NGLTF Executive Director Jeff Levi.

Organizing

The Task Force develops national organizing projects for the gay and lesbian community. NGLTF was the first to establish a nationwide, toll-free gay Crisisline; and the first to establish a national Clearinghouse for information on gay issues. Today, NGLTF directs three major organizing projects.

Anti-Violence Project

The Anti-Violence Project works to end anti-gay violence. By researching, documenting, and speaking out against the problem, NGLTF makes the violence gay people face every day visible. By educating and lobbying agencies concerned about crime, NGLTF fosters a tangible governmental response. And by providing advice, resources and technical assistance, the Task Force helps local communities and individuals fight back.

Privacy Project

Launched in response to the Supreme Court's decision in the Georgia sodomy case, the Privacy Project works full time to repeal and prevent re-enactment of state sodomy laws. Working closely with local gay organizations, the Project develops political strategies, lobbying resources, and educational materials for use in the fight. The Project also forges coalitions with feminist, labor, civil liberties and religious groups.

Resource Center

The Task Force is a national resource center for more than 2,000 local and state gay organizations. NGLTF's files, publications, contacts and staff expertise are used daily to strengthen local efforts. NGLTF's Cooperating Organization program facilitates communication among gay & lesbian groups through a monthly organizer's newsletter.

Media/Public Education

The Task Force media program battles anti-gay prejudice by securing fair and informed

Nov. 1978
Anti-gay Briggs Initiative defeated in California

Dec. 1978
NGTF releases results of first survey of private sector discrimination

Oct. 14, 1979
First National March on Washington for Gay & Lesbian Civil Rights draws over 100,000 people

Dec. 1979
NGTF presents President Carter with petition for Executive Order barring discrimination

June 1980
NGTF opens DC office

Aug. 14, 1980
Black gay activist Mel Boozer nominated for Vice-Presidency at the Democratic Nat'l Convention

Oct. 1980
NGTF v. Carlson settled, allowing federal gay prisoners access to gay publications

1981
Wisconsin state legislature passes nation's first statewide gay rights bill

Oct. 1981
NGTF launches successful national campaign to prevent passage of Family Protection Act; FPA did not pass

Sept. 1982
NGTF founds Anti-Gay Violence Project

Oct. 1982
NGTF establishes first national toll free gay hotline

Jan. 1983
NGTF spearheads Consensus Statement on national blood policy and AIDS

Jan. 1984
NGTF lobbying secures support for gay civil rights from US Conference of Mayors

July 1984
NGTF releases first national survey of anti-gay violence

© Tom DiMaria



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Media/Public Education

The Task Force media program battles anti-gay prejudice by securing fair and informed reporting about the gay/lesbian community, and by responding quickly to homophobic coverage. Over the past 14 years, the national media has come to depend on NGLTF's background briefings on issues of concern to the gay community, as well as to draw routinely on NGLTF personnel and resources for comment and information.

Jan. 1983
NGTF spearheads
Consensus Statement
on national blood
policy and AIDS

Jan. 1984
NGTF lobbying secures
support for gay civil
rights from US Confer-
ence of Mayors

July 1984
NGTF releases first
national survey of anti-
gay violence

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NGLTF staff members Michael McMahon, Urvashi Vaid and Sue Hyde at work.

Oct. 1984
NGTF obtains federal
funding for AIDS edu-
cation by community
based organizations

Jan. 1985
NGTF forges consensus
on use of antibody test
signed by gay & non-
gay groups

March 1985
US Supreme Court
invalidates anti-gay
state law which pre-
vented gay teachers
from advocating or
teaching about gay
rights in *NGTF v.
Oklahoma*

July 1986
US Supreme Court
upholds anti-gay
sodomy laws in *Bowers
v. Hardwick*

Sept. 1986
NGLTF launches
Privacy Project to work
for repeal of sodomy
laws

Oct. 9, 1986
NGLTF-sponsored
Congressional hearings
on anti-gay violence
held

Nov. 1986
LaRouche Initiative
defeated after massive
organizing by California
gay/lesbian community

Dec. 1986
NGLTF lobbying
secures pro-gay policy
from national body of
state insurance
regulators

Feb. 1987
NGLTF releases
Counterbudget '88: A
gay agenda for the
federal government

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- Cooperating Organizations receive a special monthly Organizer's Report

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- ☐ Please send me a FREE list of all Task Force Publications
- ☐ Please have someone contact me about including the Task Force in my will, and planned or deferred giving programs

And It Takes Work.

The Task Force Works.

The National Gay & Lesbian Task Force (NGLTF) is the national gay rights organization with an activist agenda for social change. The Task Force works to create a society where lesbians and gay men can live openly, free from violence, bigotry and discrimination.

Our record since 1973 proves that the Task Force works.

April 1974
Am. Psychiatric Assn.
removes homosexuality
from list of mental ill-
ness after NGTF lobby-
ing effort

Nov. 1974
First openly gay official
elected to MA state
legislature

March 1975
NGTF secures introduc-
tion of first gay rights
bill in Congress

July 1975
NGTF obtains US Civil
Service Commission
ruling allowing gay
people to serve as
federal employees

March 1977
NGTF organizes first
official White House
meeting with gay
activists

June 1977
NGTF launches "We
Are Your Children"
campaign in response
to Anita Bryant's anti-
gay campaign

Nov. 1977
NGTF women secure
pro-gay resolution at
the International
Women's Year National
Conference in Houston

April 1978
NGTF lobbying leads
to end of Public Health
Service certification of
gay immigrants as
"psychopathic
personalities"

National Gay & Lesbian Task Force
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A copy of our latest financial
report may be obtained from the
NY State Department of State,
Office of Charities Registration, 162
Washington Avenue, Albany, New
York 12231, or by writing to
NGLTF.

AIDS ADVISORY

NATIONAL GAY TASK FORCE
80 FIFTH AVENUE
NEW YORK, NEW YORK 10011
(212) 741-5800

TO: AIDS Service Organizations

FROM: NGTF AIDS Program

RE: Follow-up on Meeting with Social Security
Administration Officials

DATE: May 29, 1984

Attached is a copy of the detailed agenda we pursued at our meeting with the Acting Director of the Social Security Administration (SSA) and her staff, a meeting also attended by representatives from the Gay Men's Health Crisis, the Dallas AIDS Information Project, and the Health Education Resource Organization of Baltimore. Our thanks to these latter organizations as well as the 11 other organizations and numerous persons with AIDS who provided essential grass-roots indications of the problems that are occurring in some localities with respect to the implementation of the April 1983 policy that caused AIDS to be added to the list of recognized impairments.

As we noted in the press release that described the meeting and its outcome -- (which you were sent in early May; an additional copy is enclosed) -- some significant commitments were made by the Social Security Administration. These included:

-- their agreement to meet with physicians from the gay/lesbian community in order to define the medical criteria that could be used to reliably identify individuals that suffer from AIDS-like symptoms (sometimes referred to as AIDS-related conditions/complex or ARC) that are disabling but which do not meet the strict CDC definition. Coming as this did on the heels of AAPHR's discussion of the issue at their April 27 meeting and their offer of assistance to the SSA, agreement on an auxiliary category of disability to cover these persons now seems quite possible.

-- their agreement in the meantime to remind the state offices in charge of disability determination that they should allow benefits for applicants who fall short of the CDC definition but who are functionally disabled (a bulletin to this affect was recently approved, but we have not yet received a copy).

-- their agreement to instruct regional and local offices of the SSA to establish better liaison with and work cooperatively with AIDS service organizations (ASOs). NGTF has provided SSA headquarters in Baltimore with a listing of ASOs in the various cities and will work to facilitate communication.

-- their agreement to encourage implementation of procedures that, based on experiences in cities such as New York and San Francisco, appear to expedite the granting of benefits.

-- their agreement to investigate, with advice and input from NGTF and ASOs, ways to better publicize the availability of benefits for persons with AIDS.

We are currently conducting our initial follow-up to the meeting with the Commissioner (exchanging letters of understanding, providing information to field operations specialists, etc.). Input and assistance from service organizations and persons with AIDS in pursuing the goals agreed upon at the meeting is quite welcome:

-- We ask that AIDS service organizations keep us apprised of any problems their clients may be experiencing in gaining access to the Social Security benefits to which they are entitled. We will do all that we can to advise you in achieving remedies, and if it is necessary we can bring these problems to the attention of the SSA in Baltimore.

In particular we need to know what success persons suffering from disabling AIDS-like symptoms (a.k.a. ARC) are currently enjoying in gaining access to benefits. As we noted in the 5/2/84 press release, the SSA urges all those who are disabled to apply regardless of whether they have AIDS as defined by the CDC.

-- If you have any suggestions to offer for expediting the provision of benefits (other than those that are contained in the enclosed agenda), please do share them with us.

-- If you like to have input regarding efforts the SSA might undertake to better publicize the availability of benefits, let us know, as we are communicating with the SSA's Office of Field Operations about achieving this goal.

-- And, finally, if you have any questions about SSA policy or the disposition of a particular case, please feel free to call or write. We have attached a copy of our AIDS Advisory entitled "Applying for Social Security Benefits," which many of you have already requested and received, along with some documents of relevance to SSA policy.

NGTF contact person for questions about SSA policy: John Boring, at 212-741-5800; NGTF AIDS Program, 80 Fifth Avenue, Rm. 1601, New York, NY, 10011

Agenda for Meeting with Martha A. McSteen, Commissioner of Social Security Administration

April 30, 1984. Baltimore Maryland, 6401 Security Blvd., Altmire Bldg., 9th floor.

Attending from the gay/lesbian community: Virginia Apuzzo, Executive Director of NCTF; John Boring, NCTF AIDS Program Coordinator; Jeff Levi, NCTF's Washington Representative; Phil Gerber, a person with AIDS representing the Dallas AIDS Information Project; Peter Laqueur of the Health Education Resource Organization of Baltimore; and, Jay Lipner, Special Counsel to the Gay Men's Health Crisis.

Attending from the Social Security Administration: Martha McSteen, (Acting) Commissioner; Patricia M. Owens, (Acting) Associate Commissioner for Disability; Jean H. Hinckley, (Acting) Deputy Associate Commissioner for Disability; Janice L. Warden, Deputy Associate Commissioner, Office of Field Operations; Dr. James Krajesky, Regional Medical Advisor, San Francisco; Dr. Rein Saral, Medical Consultant Staff; Hugh Meade, Jr., Director, Division of Preadjudicative Policy; and, James MacDonald, Chief, Medical Evaluation Branch.

Purpose of Meeting:

This meeting affords the opportunity to describe implementation problems and make recommendations for their remedy. We will urge that the procedures adopted in New York City and to varying degrees replicated elsewhere be mandated or encouraged in all localities with a significant incidence of AIDS. In addition we will ask that some additional changes in procedural be considered. We will of course, give SSA credit for their special efforts in NYC and elsewhere, and for the national policy initiatives they have already promulgated.

The meeting also affords the opportunity to raise the issue of benefits for those who currently fall outside the SSA definition for AIDS disability but who do suffer from an AIDS-related condition that is frequently disabling in itself and in some cases later deteriorates to AIDS as defined by the CDC.

In summary, we are asking SSA to meet three worthy objectives:

- 1.) To agree to implement procedural improvements nationwide that will make it easier for PWAs to obtain access to SSA benefits.
- 2.) To provide PWAs with automatic referrals to other federally-funded programs (Medicaid, Foodstamps).
- 3.) To obtain a commitment from the Commissioner to supplement the existing definition for CDC-defined severe AIDS so as to cover those with debilitating AIDS-related conditions.

In general we hope to establish a dialogue between the Commissioner and the gay community that will help to resolve problems pertaining to SSA and PWAs.

Agenda and Talking Points

I. Introductory statements: (approximately 5 minutes each)

-- Apuzzo (discussing SSA's record on AIDS thus far -- positive policy initiatives; the outreach and services provided by AIDS service organizations; the current inconsistency in quality of service to PWAs; need for a nationwide commitment to better outreach and nexus with AIDS service organizations; the severity of AIDS and how that makes special consideration imperative; plight of persons with ARC).

-- McSteen or designated SSA spokesperson.

II. SSA's Presentation (see items 1., 2., 3., 4., and 5. of their suggested agenda -- at our suggestion they will not belabor basic facts about SSI and SSD).

After the SSA presentation, we will have the opportunity to ask clarifying questions. The following questions have already been proposed:

-- Have they intervened in any cases under review? (Blumenfeld said no in October)

-- What conclusion have they reached thus far? (Blumenfeld said working well for those with CDC defined; also including a few with long-established severe prodromal; among the 5% rejected were others with AIDS-like conditions)

-- Is there a category included in the 909 applications sent to SSA headquarters that were incomplete? (80 out of 425 applications as of September)?

-- Were any CDC defined cases denied benefits?

-- How do they explain that fewer than 900 persons have obtained benefits thus far (Of the 909 applications SSA reports that 95% or at most 864 were approved), when over 4000 persons have been diagnosed and over 3,500 have been alive during the time that the new policy has been in existence (i.e., since April 83).

-- What is the availability of Teleservice to PWAs outside of Washington and New York?

-- Are home visits by SSA District Offices (DOs) representatives generally supposed to be available to PWAs whose mobility is limited?

-- What leeway do the state offices of disability determination have in implementing Presumptive Disability (PD) in the case of AIDS? Assuming the regulation allowing DOs to allow under a ruling of PD is approved by the Secretary, what leeway will they be permitted in using PD for AIDS claims?

III. Presentation by NGTF, Dallas AIDS Project, and GMHC

A. NGTF: Summarize implementation problems of current policy (results from national survey of Persons with AIDS and AIDS service organizations in 16 cities)

1.) The waiting period for obtaining SSI payments -- which we define as the period that elapses between the date of application and the date payments are received -- varies considerably among the different cities and, in some cases varies among individuals within the same city. For example:

-- In Atlanta, GA, AID Atlanta reports that their clients are not obtaining benefits until 3 to 6 months after applying.

-- In Los Angeles, delays varying from 6 weeks to 5 months have been reported.

-- The SF AIDS Foundation reports considerably better and more consistent service: PWAs who come to them are typically receiving benefits in 2 to 3 months.

-- In Seattle and also in Boston delays of 6 to 12 weeks are currently reported.

-- In Baltimore, delays are not as long, but still vary widely, from 3 to 8 weeks.

-- In NYC, the waiting period is shorter and more consistent between individuals: 4 to 6 weeks.

It is difficult not to conclude that in fairness to PWAs across the country, there is no valid excuse for delays longer than those that occur in NYC.

It is of course true that SSI payments are retroactive to date of application when they do arrive. But, consequences of a prolonged delay can be considerable: we are aware of instances where PWAs awaiting SSI benefits have had to forgoe proper nutrition for lack of money -- even when interim assistance is available from state and local welfare, these sums are often substantially less than what is available under SSI. The implications in terms of medical care can be quite serious: since in most states eligibility for Medicaid depends on having been improved for SSI, inordinate delays in SSI has in some cases caused medical care to be withheld. And since, Medicaid will only pay retroactively back a maximum of 90 days, delays in SSI exceeding this length of time can result in an outright loss of benefits. In addition to these tangible effects on the quality of life and medical care, the uncertainty and worry that result from lengthy and sometimes inexplicable delays translates into additional psychological stress which can sometimes hasten the decline of the claimant.

On account of the statutory waiting period for SSD eligibility (Social Security Disability Insurance) unexpedited processing is typically of less consequence. However, in cases where application is not made until 5 months after onset of illness, the applicant can suffer from the same long delays. (Note: Phil Gerber has been in precisely this situation.)

It is not always possible to deduce the cause or causes of delays exceeding 6 weeks. However, we have found evidence of causation in several areas:

Some state offices of disability determination may not be following SSA guidelines, thus contributing to delays.

-- In California we have heard that the state as a matter of course is not allowing SSI for persons with AIDS under a ruling of Presumptive Disability.

-- Elsewhere, -- for example in Baltimore, MD, and Atlanta, GA, -- the use of PD for expediting SSI has been inconsistent.

-- Generally speaking, it appears that PD is more widely utilized since issuance of the Dec. 23, 1983 Program Circular.

-- There is currently pending a case in Georgia of claimant with clear CDC defined AIDS who was rejected for benefits on the grounds that not disabled. Applied in October; has disseminated herpes simplex (a listed OI) plus CMV in eyes threatening blindness. Was subjected to vocational test that indicated he could lift 10 lbs. and therefore should be working. Has just been notified that he will receive a reconsideration.

-- In Massachusetts, the Mass. Rehabilitation Commission is not allowing the phone transcripts of conversations with physicians to suffice for verification of AIDS diagnoses for purposes of PD and are instead requiring copies of hospital records; in all other impairment categories they are permitting the use of phone transcripts. It is estimated that as a result delays are increased by up to 3 weeks.

-- Some among the medical evaluation staff may not be aware of the fact that a case of AIDS can vary over time in the severity of its expression: in Baltimore, for example, a PWA is now undergoing a 12 month reevaluation, and because he has for the moment partially recovered from his OI has been told he may no longer be considered disabled even though he has not (nor has anyone) recovered from AIDS.

Some personnel in SSA DO may be poorly informed about SSA policy pertaining to PWAs

-- We continue to hear reports of SSA personnel are not always as informed as they ought to be regarding the availability benefits to PWAs, their availability under a ruling of PD, and are unable to answer questions regarding the availability of teleservice, home

visits. These reports typically decline in localities as their experience in handling AIDS cases and working with advocates from AIDS Service Organizations increases.

It is our belief that the bulk of the inordinate delays -- where they have occurred -- can be explained by the fact that some personnel in the SSA DOs and the Disability Offices do not fully understand how incapacitating AIDS can be and the consequent need to provide an extra measure of service. The trial of the application process -- standing in long lines, etc., having to aggressively pursue the records needed for medical and financial verification -- is sometimes beyond the physical and mental capabilities of those most severely impaired by AIDS. Personnel in some cases have not understood the fact that PWAs may require more staff time in providing explanations and basic information in order that filing requirements can be comprehended and fulfilled. Similarly, follow-up is not always adequate, and we have heard reports that personnel are not always prepared to work with third party advocates who may accompany claimant for an interview. At least as they have been described to some PWAs and AIDS advocates, Teleservice and in-home interviews are sometimes fraught with bureaucratic limitation so as to be not very useful for the PWA.

In some localities it would appear that not everything is being done that could be done to expedite processing of AIDS claims. For example, it is reported from a source familiar with the processing of AIDS claims in Massachusetts that the time taken to accomplish financial verification has been excessive: rulings of PD have not speeded up the arrival of benefits since final medical allowance typically precedes financial determination. Due largely to the efforts of the AIDS service organization in Boston and the efforts of some concerned personnel within disability determination, delays in that city have decreased markedly from what they were 6 months ago; however, further improvements there and elsewhere now depend on enhanced commitment from the SSA.

These delays still appear to be related in some part to nature of illness and the minority group status of those typically affected:

Without question, Secretary's Heckler's letter last summer has mitigated this problem, and we do appreciate that and the educational efforts that this letter has spawned in many local DOs. However, we do still hear occasional reports of discourtesy from PWAs, and of delays linked to reluctance to handle AIDS claims, indicating that reemphasis of the points made in the Secretary's letter would be beneficial.

While it is true that hospitals, medical practitioners, and financial institutions can themselves be responsible for delays, experience demonstrates that SSA personnel can intervene successfully in order to expedite delivery of essential information. In New York and elsewhere, outreach on part of personnel has been essential to reducing the waiting period for benefits. For example: the exemplary performance and concern demonstrated by the DO in lower Manhattan.

Conclusion of NGTF's presentation:

When these problems have been remedied in a systematic and lasting fashion -- Jay and Phil will describe some successes at the local level -- it has largely been the result of the perseverance of a few determined claimants and at the behest of the volunteers and staff of AIDS service organizations. However, success was only possible when their efforts were met by cooperation and spirit of outreach that characterizes the finest public employees. The clearest generalization that we can derive from our contacts with AIDS service organizations around the country is that cases were most easily expedited and problems are most easily remedied once they have succeeded in establishing liaison with officials of the SSA and/or disability determination offices. Whether they were self-designated or designated with the tacit approval of supervisors, those who specialized in AIDS claims have inevitably proved those best able and best motivated to meet the needs of persons with AIDS.

B. Problems encountered in Dallas; Phil Gerber's personal perspective as a claimant; waiting 6 months before the arrival of benefits; not all PWAs are so lucky to be associated with an AIDS service organization, to become well enough to recommence work.

C. GMHC: summarize the New York City Model, current status of implementation in NYC.

-- special Teleservice # for AIDS applications.

-- automatic follow-up on cases where no response from claimant two weeks after call to Teleservice or initial visit to SSA district office; phone call, field visit if necessary.

-- attachment of notice to forms reminding claimant that should sign and send in forms the day they are received in order to establish earliest possible date of application.

-- Note: one NYC initiative -- exclusion from deferral of nondisability development -- has already been implemented.

E. Recent implementation of teleservice for AIDS cases in the Washington area.

F. Another problem which has become apparent in NYC and elsewhere: The Need for the SSA to assist PWAs in becoming more

aware of availability of Medicaid benefits. In states such as New York where Medicaid is available to the "Medically Needy," i.e., not just SSI recipients, Medicaid can be applied for separately, and doing so can expedite the arrival of this coverage which is often essential to PWAs if they are to obtain prompt medical care. Principal of referral applies equally well to foodstamps, another federally funded program.

G. The Predicament of those disabled with AIDS-like conditions. What we have described thus far are problems that can be solved by modification of current procedures and by more careful follow-through on policy initiatives already promulgated by the SSA, (and we shall shortly provide recommendations for doing just that). There is another problem that has not yet been addressed by the SSA and which will require a major policy initiative. For more than a year we have been receiving reports of persons who display many of the symptoms and clinical indications of AIDS and have been medically classified as having prodromal AIDS or AIDS-related Condition (ARC). Many of these persons are disabled: suffering from debilitating fatigue, and lymphadenopathy that may be so severe as to restrict movement. Prospective epidemiologic studies indicate that a significant percentage of ARC cases later -- frequently within a period of a year -- deteriorate to AIDS as defined by the CDC. Often all that is missing in terms of a diagnosis is a recognized opportunistic infection.

As will be noted in several examples, many of those suffering from prodromal AIDS who do apply for benefits have ultimately qualified, but only after their health status has deteriorated and they have developed the OI that qualifies them for benefits. In some cases it can be argued that the denial of benefits hastened their decline.

Those charged with medical evaluation at the disability determination centers are often in a quandry when confronted with claims involving severe ARC. Sequential evaluation seems still to exclude too many who fall into this category. In fact we are aware of only one case -- a recent case, in Massachusetts -- of a claimant with ARC who was allowed benefits according to vocational considerations contained within the sequential evaluation process. (Note: Blumenfeld indicated last September that he was aware of a couple of cases of severe prodromal AIDS that had been allowed by the states according to the "equal to" provision, but this was only after symptoms had been present for 12 months or longer).

Some typical ARC cases:

-- San Francisco: Applied in August 1983, rejected in October, develops KS in December, obtains after a hearing in January.

-- San Francisco: case pending, lymphadenopathy, chronic oral thrush, severe disabling fatigue.

-- Atlanta: Applied in November, has lymphadenopathy, chronic fever, fatigue, unable to retain job, rejected in January, due for a hearing on May 4. Cannot get medicaid on account of not qualifying for SSI, similarly, public hospitals reluctant to subsidize updated blood chemistry work that would help to bolster medical evidence of ARC.

-- New York City: report from social worker at Roosevelt Hospital that many with severe ARC are treated but they rarely apply for benefits, believing -- with some justification -- their chances to be nil.

-- Dallas: case which recently came to the attention of his organization of claimant who had been rejected twice, unable to work, has in desperation sought help from a lawyer.

For all the cases we know about, there are probably many others where the persons suffering from ARC are discouraged from applying, knowing full well that is very unlikely benefits will be awarded in the absence of an OI.

We do not propose that we attempt to negotiate a medical definition of ARC at this meeting. However, for your edification, we would like to present copies of a letter from the NYPHR and a copy of a memorandum from the San Francisco AIDS Foundation, both of which have a bearing on this issue. And we will make reference to this problem in our recommendations.

IV. Recommendations:

A. Recommend adoption of NYC model in localities with a significant incidence of AIDS.

B. Recommendation for improving awareness of other Programs

o In order to ensure that applicants are adequately aware of other federally-funded programs for which they may be eligible, urge Automatic referral at time of application to Medicaid offices in those states with programs serving the "medically needy."

o To ensure that those claimants in states where Medicaid is available to the "categorically" needy obtain their cards as expeditiously as possible after SSI is allowed, we ask that SSA notify the state office charged with dispensing Medicaid cards immediately by phone.

C. Some recommendations that go beyond the NYC model but which are strongly suggested by our survey of local implementation, and in some cases are already being implemented de facto.

- o SSA should require the designation of staff person(s) who would specialize in the handling of AIDS claims in all districts with a significant incidence of AIDS. (fall back position: issue letter encouraging this action).
- o This designated person should obviously work in connection with the teleservice line(s) made available to persons with AIDS.
- o In states with a significant incidence of AIDS, a claims officer should be designated in the office charged with disability determination who would similarly handle or oversee the processing of all AIDS claims in that state.
- o As part of the application process, PWAs should have the option of calling to make an appointment with a claims officer, rather than necessarily having to endure long waits in SSA offices.

D. Recommendations to improve outreach and nexus between the SSA and AIDS service organizations.

- o Since AIDS service organizations are best prepared to assist persons with AIDS, SSA should make referrals to ASOs, in localities where they exist.
- o In a spirit of outreach local SSA District Offices (DOs) should establish liaison with AIDS service organizations. Since many of the problems surrounding AIDS applications seem to result from an insufficiently knowledgeable or responsive bureaucracy:

E. Recommendation for reinforcing comprehension of existing policies

- o We ask that a special advisory be sent out to SSA offices and State Disability Determination offices that would summarize (and thus reinforce) all existing AIDS-related communications and would discuss the special situation of the person with AIDS (severe fatigue, possible disorientation, etc.), the need for particularly attentive service, and the desirability of welcoming the assistance of an advocate from an AIDS service organization.
- o Furthermore, District Offices and Disability Determination offices should be reminded of the episodic nature of AIDS so that they can take that into account when conducting their periodic reviews of recipients.

Note: the value of having this and other policy statements written down; for use in advocacy; so PWAs can know what their rights are.

F. Recommendation for development of a new definition that will allow persons disabled with AIDS-related conditions to obtain benefits

o Recommend that SSA consider changes in definition, (or changes in procedure that would have the same effect.) Possible approaches might include:

- Create a new or auxilliary definition for ARC.
- Expand SSA definition, per NYPHR or some other formula.

Note: The latter is more problematic in that it might bring the SSA definition into contradiction with the CDC definition; SSA might object on these grounds. However, we can note that Curran is on record saying that the CDC definition is a tool for epidemiology and should not necessarily be used for social services. There is nothing to prevent development of an auxillary definition for ARC, and this is probably preferable in that avoids our appearing to suggest that all prodromal persons -- which might number in the tens of thousands -- are necessarily as ill as those with CDC defined AIDS. In fact they probably aren't -- only some fraction of ARC will be in need of benefits. For this reason it is not wise to raise the question of PD for ARC claims -- leave that and other details for the doctors to resolve.

Other approaches for resolving this problem they might make:

- Expand definition per anticipated changes in CDC definition (utilizing the new test).

This is undesirable since we do not know how long it will take for CDC to revise. A blood test may eventually be useful to confirm an AIDS-related disability, but strategically unwise to link at this time.

Clearly we should insist upon one of these concrete changes, as opposed to more nebulous commitments to procedural changes, such as:

- Mandate procedural changes that make it easier to allow benefits according to the "equal to " provision.
 - Mandate procedural changes that make it easier to allow benefits according to the sequential evaluation process.
- (Ginny) There are physicians that stand ready to assist you in this regard. The meeting tomorrow in New York will provide that first opportunity (Drs. Seitzman and Enlow will be present.)

Can note that Dr. Passer of NYPHR just this last week informed us that AAPHR was prepared to provide 3 doctors with expertise in this matter -- they and others stand ready to assist in this matter -- they and others stand ready to assist SSA in devising definition to cover ARC.

V. DISSCUSSION:

General discussion of our recommendations with the Commissioner and her staff.

Some points to keep in mind in the course of this discussion:

-- SSA has proved itself capable of extending itself to meet the needs of CDC-defined PWAs in NYC. If it is possible in NYC, why not elsewhere?

-- Business as usual can't apply in the case of persons suffering from an illness as debilitating as AIDS. In many cases fatality results within two years of diagnosis. Ordinary delays cannot be tolerated for an extraordinary illness.

-- The state offices charged with disability determination are definitely within the regulatory jurisdiction of the Commissioner.

Social Security Administration-National Gay Task Force Meeting

Social Security Headquarters

April 30, 1984

OBJECTIVE

To discuss the issues and problems relating to the evaluation of acquired immune deficiency syndrome (AIDS) cases when determining disability under titles II and XVI of the Social Security Act.

AGENDA

<u>TOPIC</u>	<u>PRESENTER</u>
• Welcome and Introductory Remarks	Acting Commissioner McSteen
• Introductions	National Gay Task Force (NGTF) and Social Security Administration (SSA)
• SSA's Evaluation Criteria for AIDS	Medical Consultant Staff
• SSA's Experience With AIDS	Office of Disability
• SSA's Ongoing Review of AIDS Cases	Medical Consultant Staff
• Question and Answer Period	All Participants
• NGTF's Concerns With SSA Policy Regarding AIDS Cases	NGTF
• Discussion and Recommendations	All Participants

LIST OF PARTICIPANTS

SSA

Martha A. McSteen
Acting Commissioner of SSA

Patricia M. Owens
Acting Associate Commissioner
for Disability

Jean H. Hinckley
Acting Deputy Associate Commissioner
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Washington Representative,
National Gay Task Force

John Boring
National Gay Task Force

Jay Lipner
The Gay Men's Health Crisis

Philip Gerber
The Dallas AIDS Project

NGTF

AIDS Update

NATIONAL GAY TASK FORCE
80 FIFTH AVENUE
NEW YORK, NEW YORK 10011
(212) 741-5800

STATEMENT ISSUED BY NGTF ON MARCH 29, 1984, IN RESPONSE TO
PROPOSALS FOR CLOSURE OF THE BATHHOUSES:

The National Gay Task Force understands -- and shares -- the concern and grief over the continuing AIDS epidemic which has led some members of the San Francisco gay/lesbian community to request that the Public Health Department close establishments catering to sex with multiple partners. However, NGTF feels most strongly that personal behavior should not be regulated by the state, which historically has been an instrument of our oppression. Furthermore, state closure of such establishments would be a largely symbolic gesture that would provide a false sense of security that the AIDS epidemic had somehow been contained. It would constitute a deceptive and simple answer to a very complex problem.

At the same time, NGTF recognizes the need for the gay/lesbian community to further accelerate educational efforts. The evidence is increasingly clear: anonymous sex with multiple partners places those who participate at much higher risk to Acquired Immune Deficiency Syndrome. Because we care about the good health of each and every member of our community, we consider it imperative that this information be made known.

NGTF'S RESPONSE TO SAN FRANCISCO HEALTH COMMISSIONER
SILVERMAN'S DECISION TO BAN SEXUAL BEHAVIOR IN BATHHOUSES
(4/9/84):

The National Gay Task Force feels most strongly that consensual sexual behavior between adults should not be monitored or regulated by the state, which historically has been an instrument of oppression for gay and lesbian Americans. Efforts to police the private sexual behavior of individuals raise the spectre of unwarranted intrusion by government.

At the same time, NGTF recognizes the need for the gay/lesbian community to further accelerate educational efforts to combat the AIDS epidemic. The evidence is increasingly clear: certain kinds of sexual behavior appear to place those gay men who participate at much higher risk to AIDS, and the risk appears to multiply with the number of partners. Because we care about the good health of each and every member of our community, we consider it imperative that this information be made known -- so that individuals can make an informed decision not to participate in high risk behavior, without interference from the state.

AIDS MATERIAL AVAILABLE FROM THE NATIONAL GAY TASK FORCE

1. AIDS Health Care Packet: (contents on back).

2. Person with AIDS Packet:

- 1) Answers about AIDS (Gay Men's Health Crisis, NY).
- 2) A Guide for People with AIDS (AIDS Action Committee of Ken West, FL).
- 3) Personal Advocacy for People with AIDS and ARC (McGahee, AID Atlanta).
- 4) Confidentiality Statement & article (NGTF).
- 5) Recommendations from Workshop on Meeting Needs of PWAs (Denver Lesbian/Gay Health Conference).
- 6) Health Letter #2 (GMHC).
- 7) NGTF SSI/SSA information:
 - a) "Applying for Social Security Benefits: The Basic Facts."
 - b) Lambda Legal Defense Fund (New York) list of gay organizations assisting with claims or AIDS-related discrimination.
 - c) Chart: Medicaid Services State-by-State (Dept. of Health and Human Services (Washington, D.C.)).
 - d) Press Release: "NGTF Discusses Medicaid Eligibility Rules with Administration Officials."
 - e) NGTF AIDS Advisory: Some Documents Relevant to Social Security for Persons with AIDS:
 1. SSA press release on evaluation and definition of AIDS for SSA qualification.
 2. SSA program circular: Disability Insurance.
 3. Margaret Heckler memo on AIDS and fear of transmission by casual contact.
 4. Dr. Brandt letter regarding casual contact and SSA employees overreaction to claimants.
 5. SSA Teleclaims Application Filing Procedure for AIDS victims (sic).
 6. 1/5/84 state-by-state breakdown on AIDS claims.

3. Gay General AIDS Information Packet:

- 1) Answers about AIDS (Gay Men's Health Crisis, NY).
- 2) Guidelines for AIDS Risk Reduction (Bay Area Physicians for Human Rights, CA).
- 3) Guidelines and Recommendations for Healthful Gay Sexual Activity (National Coalition of Gay STD Services, WI).
- 4) Viral Hepatitis: Risks/Precautions/Prevention for Gay Men (Hepatitis Info Center/Abbot Labs).
- 5) NGTF Crisisline description page and card.
- 6) HTLV-3 update and commentary (GMHC).
- 7) Federal Funding Update (NGTF).

4. Non-Gay High-Risk AIDS Information Packet:

- 1) Answers about AIDS (Gay Men's Health Crisis, NY).
- 2) NGTF Crisisline description and card.
- 3) HTLV-3 update and commentary (GMHC).
- 4) Federal Funding Update (NGTF).
- 5) Spanish AIDS pamphlet (GMHC).
- 6) Creole AIDS pamphlet (Haitian Coalition on AIDS, NY).
- 7) Shooting Up and Your Health (Haight-Ashbury Free Medical Clinic, CA).
- 8) AIDS and Hemophilia: Questions and Answers (National Hemophilia Foundation, NY).

1) HEALTH CARE PACKET @ \$7.50

2) PERSON WITH AIDS PACKET *

3) GAY GENERAL AIDS INFO PACKET*

4) NON-GAY HIGH-RISK AIDS INFO PACKET*

Quantity

Total

Name & Address _____

FINAL TOTAL —

* Sent free to Crisisline Callers (though bulk orders are charged for postage and duplication).

- 1) Cover letter/description with receipt or bill.
- 2) NGTF AIDS Resource Directory: Current listings of AIDS services and resources nationwide.
- 3) "Answers about AIDS" - question & answer overview. (Gay Men's Health Crisis, New York).
- 4) Health Letter #2: AIDS update (GMHC).
- 5) Spanish AIDS pamphlet (GMHC).
- 6) Creole AIDS pamphlet (Haitian Coalition of AIDS, New York).
- 7) "AIDS and Hemophilia: Questions and Answers" (Hemophilia Information Exchange, National Hemophilia Foundation, New York).
- 8) "Good Nursing Care and the AIDS Patient" pamphlet (Health Education Resource Organization (HERO), Baltimore).
- 9) "Advice for Health Care Professionals" article (Howard Brown Clinic, Chicago).
- 10) "Overview of Psychological Issues Covering AIDS" (GMHC).
- 11) "Infections Frequently Associated with AIDS (Manifestations/Treatment/Precautions)" (NYU Medical School/GMHC).
- 12) Order forms: AIDS Syllabi (University of California Nursing Education), Health Care Provider Packet (KS/AIDS Foundation, San Francisco).
- 13) "Guide for People with AIDS" (AIDS Action Committee of Key West).
- 14) Bob Cecci (PWA) speech and Michael Callen (PWA) profile (Long Island Connection, NY).
- 15) Biographies: KS/AIDS Foundation, S.F. (one-page description).
- 16) Canadian Gay Archives, Toronto (two-page description).
- 17) General population AIDS pamphlet (San Francisco Health Department).
- 18) Viral Hepatitis pamphlet (Abbot Labs, Chicago).
- 19) Poster: "Precautions for hospital personnel treating possible AIDS patients" (Abbot Labs).
- 20) NGTF SSI/SSA information:
 - a) "Applying for Social Security Benefits: The Basic Facts,"
 - b) Lambda Legal Defense Fund (New York) list of gay organizations assisting with claims or AIDS-related discrimination.
 - c) Chart: Medicaid Services State-by-State (Dept. of Health and Human Services (Washington, D.C.)).
 - d) Press Release: "NGTF Discusses Medicaid Eligibility Rules with Administration Officials."
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 4. Dr. Brandt letter regarding casual contact and SSA employees overreaction to claimants.
 5. SSA Teleclaims Application Filing Procedure for AIDS victims (sic).
 6. 1/5/84 state-by-state breakdown on AIDS claims.
- 21) NGTF AIDS Services Compilation (Services locally and nationally available to people with AIDS and the gay/lesbian community).
- 22) NGTF membership brochure.
- 23) Description of Crisisline and Violence Project.
- 24) Packet of Crisisline cards.
- 25) "Guidelines for AIDS Risk Reduction" (Bay Area Physicians for Human Rights, San Francisco).
- 26) "Guidelines for Healthful Gay Sexual Activity" (National Coalition of Gay STD Services, Milwaukee).
- 27) NCGSTDS fact sheet and membership form.

* \$7.50 is charged for the packet to cover duplication and postage.

NGTF AIDS ADVISORY: DOCUMENTS RELEVANT TO SOCIAL SECURITY AND AIDS

1. Press release dated May 2, 1984: "NGTF Meets with Social Security Commissioner to Discuss AIDS Benefits." Describes 4/30/84 meeting between gay/lesbian community representatives and Acting Commissioner McSteen and her staff at which implementation problems and remedies for their solution were discussed.
2. Memorandum dated 9/13/84 from San Francisco AIDS Foundation re regarding the "Social Service Needs of ARC Patients." Suggests that a workable definition of AIDS-related conditions be developed for the purposes of qualifying for disability entitlements such as SSI and SSDI.
3. Letter dated 12/1/83 from the New York Physicians for Human Rights suggesting an expanded definition of AIDS encompassing those suffering from severe AIDS-like conditions; definition would be for the purposes of disability determination.
4. Social Security Administration transmittal dated February 28, 1984, sent to local SSA offices instructing them to begin financial verification ("nondisability development") without waiting for state offices of disability determination to pronounce the claim medically valid, as is the case for some disabilities.
5. SSA Program Circular: Disability Insurance: "Presumptive Disability, New Impairment Category -- AIDS," December, 1983. Issued by the SSA to state disability determination offices to remind them that persons with AIDS can be granted benefits on a ruling of "Presumptive Disability."
6. Memorandum dated July 7, 1983, from Margaret Heckler, Secretary of the Department of Health and Human Services, to all SSA employees on the topic of "Concern about the Transmission of Acquired Immune Deficiency Syndrome (AIDS)." This was issued to quell irrational fear of AIDS among Social Security personnel.
7. Memorandum dated June 22, 1983, from Assistant Secretary for Health, Dr. Edward Brandt, to Margaret Heckler, concerning the transmission of AIDS. This memo accompanied Heckler's memo (#3 above) and was sent to convince SSA personnel that any fears they might have of contracting AIDS in the course of interviews or the processing of papers were medically unjustified.
8. Teletyped transmittal to state offices of disability determination from Social Security Administration dated July 15, 1983, describing addition to the SSA manual, section E2200: "Evaluation of Acquired Immune Deficiency Syndrome." This made permanent the April 26, 1983, temporary instruction and provides the medical criteria that are currently in use for deciding if a persons with AIDS will qualify for benefits.

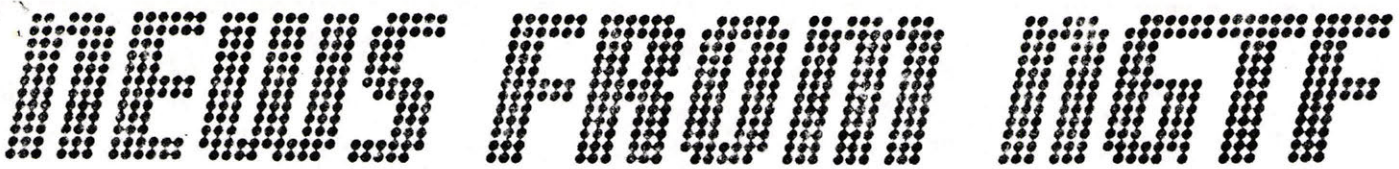
9. Expanded version of section E2200 of the SSA manual, "Evaluation of Acquired Immune Deficiency Syndrome," utilized by New York State Department of Social Services Office of Disability Determinations. Reflects the federal guidelines that each state is obliged to follow, but also provides discussion of how cases of AIDS that technically lie outside the strict SSA definition can be allowed according to the "equal to" provision of federal disability regulations.

10. "SSA Teleclaims Application Filing Procedure for AIDS Victims." One sheet guidelines provided by SSA Region 2 (covering New York, New Jersey, and Puerto Rico) describing how to apply for SSI/SSDI by telephone; for the benefit of persons with AIDS and those who may be filing applications on their behalf.

11. "AIDS Report," originating from the SSA's "Medical Consultant Staff of the Office of Disability", and obtained from the Committee on Government Operations. Lists the number of claims that were allowed (564) or denied (33) for each state as of January 5, 1983. Please note that as of NGTF's April meeting with SSA officials, the total number of allowances had risen to over 850.

12. Listing of local Social Security Administration offices in your state; addresses and telephone numbers are accessed by zip code. These are the offices where persons with AIDS -- either by phone or in person -- can begin the application process for benefits.

13. Listing of state-run offices of "Disability Determination" for your state; these offices are in charge of making the medical determination of an AIDS-related application for Social Security benefits; medical information provided at the time an application is filed with SSA is evaluated by these offices.



National Gay Task Force
80 Fifth Avenue • New York, New York 10011
(212) 741-5800

Further Information:
Virginia M. Apuzzo: (212) 741-5800

For Immediate Release
May 2, 1984

NGTF MEETS WITH SOCIAL SECURITY COMMISSIONER TO DISCUSS AIDS BENEFITS

Representatives of the National Gay Task Force and three AIDS service organizations met with the Commissioner of the Social Security Administration, Martha McSteen, on April 30th to establish new channels of communication between that agency and the gay/lesbian community. NGTF Executive Director Virginia Apuzzo described this meeting as "part of NGTF's continuing effort to educate the federal bureacracy regarding the needs of persons with AIDS."

Also attending the meeting were Jeffrey Levi, NGTF's Washington Representative; John Boring, NGTF's AIDS Program Coordinator; Jay Lipner, special counsel to Gay Men's Health Crisis of New York; Phil Gerber of the Dallas AIDS Information Project; and Peter Laqueur of the Health Education Resource Organization of Baltimore. In addition to the Commissioner, attendees from the Social Security Administration (SSA) included Patricia Owens, Acting Associate Commissioner for Disability; James McDonald, Chief of Medical Evaluation; and Janice Warden, Deputy Associate Commissioner of the Office of Field Operations.

Among the issues raised by NGTF and the AIDS service organizations were inordinate delays experienced by some persons with AIDS before gaining access to Supplemental Security Income (SSI) and Social

Security Disability Insurance (SSDI); and failure on the part of some state disability determination offices to follow SSA guidelines for expediting applications for AIDS claimants. Gerber provided his own personal perspective as a person with AIDS and claimant for benefits: "Only after much frustration, and countless inquiries on my part, and only after I had to endure repeated requests for irrelevant information and a six month wait, did I finally receive benefits."

Among the specific steps that the SSA was urged to take to make it easier for persons with AIDS to obtain benefits were: adoption of special teleservice numbers for receiving applications from persons with AIDS and implementation of systematic follow-up procedures for AIDS claims (procedures already in effect in New York City) and designation of SSA personnel to specialize in AIDS claims and work with AIDS service volunteers, which has already happened in San Francisco and a few other cities.

The need for better entitlement education directed towards persons with AIDS and closer cooperation between the SSA and AIDS service groups was also discussed. Lipner urged that the SSA provide AIDS applicants with referrals to the Medicaid program, noting that "in states such as New York, Illinois, California, and Massachusetts, where it possible to obtain Medicaid before qualifying for SSI, it is highly desirable for persons with AIDS to apply separately for Medicaid."

Commissioner McSteen agreed to take further measures to encourage expedited handling of applications from persons with AIDS, especially in those localities such as Dallas and Atlanta where delays have been particularly excessive. She also pledged better communication by her agency with AIDS service organizations and agreed that AIDS claimants would be provided with Medicaid referrals and information about local

AIDS service organizations. The gay/lesbian community will receive the names of local and regional liaisons who specialize in the handling of AIDS claims. In addition, the Commissioner recognized the need for SSA to make the availability of benefits better known to those who are eligible. It was agreed that SSA would consider public service announcements to achieve this goal.

To alleviate the plight of those who suffer from AIDS-related conditions that are severely debilitating, NGTF asked the Social Security Administration to supplement the existing definition covering only CDC (Centers for Disease Control)-defined AIDS, with a new impairment category (or categories) that will make it easier for these persons to obtain badly needed support. The Commissioner and her medical evaluation staff agreed to begin discussions with physicians from the gay/lesbian community experienced with these AIDS-related conditions. In the meantime, the SSA agreed to send a bulletin to those in charge of disability determination in every state advising them that AIDS claims falling short of the CDC definition may be allowed if the applicant is unable to perform work.

Apuzzo said the meeting "demonstrates a willingness on the part of Social Security to be more responsive to the needs of persons with AIDS and to move beyond the helpful but not wholly adequate policy initiatives that they have made in the past year." She stated that the meeting was "reflective of NGTF's ongoing commitment to bring the community's concerns around AIDS to the highest levels."

Persons with AIDS may call the NGTF Crisisline (800-221-7044); in NYS call: 212-807-6016) to obtain basic information regarding the application process for benefits obtainable from the Social Security Administration. NGTF urges persons with AIDS and those who are disabled as a result of AIDS-related conditions to apply for benefits; those experiencing problems or delays should contact their local AIDS service organization or NGTF.

AIDS/KS FOUNDATION

ACQUIRED IMMUNE DEFICIENCY SYNDROME - KAPOSI'S SARCOMA RESEARCH & EDUCATION FOUNDATION, INC.
P. O. Box 14227 (A Nonprofit Corporation) San Francisco, CA 94114

MEMORANDUM
13 September 1983

TO: Dr. Silverman

FROM: Ed Power

RE: Social Service Needs of ARC Patients

SUMMARY

When the severity of the AIDS epidemic became apparent, many social service programs altered their regulations to accomodate the needs of people with AIDS. Unfortunately, the definition of AIDS which is used to determine eligibility for these special considerations is a restrictive one which excludes many people who have debilitating AIDS Related Conditions (ARC). In order to sufficiently meet the social service needs of people affected by AIDS, it is essential that social service programs recognize and accomodate the needs of people with AIDS Related Conditions.

THE AIDS DEFINITION

The definition of AIDS, as designated by the Centers for Disease Control, requires:

The presence (culture or biopsy proven) of a disease which is at least moderately predictive of a defect in cell-mediated immunity occurring in a person with no known cause for diminished resistance to that disease.

Using this definition, the Social Security Administration has decided that people with Kaposi's Sarcoma, pneumocystis carinii pneumonia and a number of other opportunistic infections (See Attachment) are eligible for disability benefits. Following this lead, a number of other local and state social service programs have opened disability programs to people who meet this definition of AIDS.

While these changes have greatly helped individuals who have CDC defined AIDS, the restrictive nature of the definition has excluded many people with AIDS Related Conditions from the social services that they need.

AIDS RELATED CONDITIONS

To understand the restrictive nature of the CDC's definition of AIDS, it is important to review the criteria upon which the definition is based. AIDS is believed by most researchers to be an impairment of cellular mediated immunity caused by an infectious agent, probably a virus. Once the immune system has been damaged by the putative AIDS agent, the patient is at risk for contracting a host of opportunistic infections (OI). The CDC's definition of AIDS, however, does not recognize the disease syndrom until the patient has contracted one or more of the currently recognized OI. As a result, social service programs which use the CDC's AIDS definition do not meet the needs of patients who have impaired immune systems but who do not have a recognized OI. Ironically, it is often precisely these individuals who need to avoid the stresses of working and of meeting financial obligations if they hope to keep from developing a life threatening OI. These are the patients who are now being loosely lumped under the term ARC.

An ARC patient, then, would be one who has laboratory findings indicative of an immune impairment (T-cell ratio, WBC, etc.) and symptoms indicative of AIDS related disorders. The most widely recognized ARC condition is chronic lymphadenopathy,(1) usually accompanied by one or more of the following symptoms:

diarrhea	night sweats
perirectal HSV lesions	fever
herpes labialis of marked severity	fatigue
headaches	weight loss
depression and/or anxiety	skin infections

In some lymphadenopathy cases, the nodes enlarge to a point where the range of motion is restricted, or where nerve compression results.

There is a good deal of evidence to suggest that, in many cases, ARC may be a precursor to the development of CDC defined AIDS. According to the MMWR of 5/21/82, 23% of PCP patients, 44% of KS patients and 100% of patients with diffuse undifferentiated non-Hodgkin's lymphoma reported a lymphadenopathy phase prior to the development of the recognized AIDS illness. Enlow reported that 11% of the lymphadenopathy patients in his study developed KS; and Metroka noted that 17% of the lymphadenopathy patients in his study went on to develop CDC recognized AIDS diseases (6% KS, 4% PCP, and 7% diffuse undifferentiated non-Hodgkin's lymphoma).

If ARC is indeed often a pre-AIDS condition, it is essential that social services be made available to ARC patients. Removing the stress and fatigue of working may be an important component in preventing the development of life-threatening OI in the ARC patient.

Some researchers have speculated that not all ARC cases are 'pre-AIDS.' It is possible that some individuals--for reasons unknown--do not develop 'full-blown' AIDS when exposed to the causative agent. Instead, they may simply develop ARC. In any case, the symptoms of ARC are often in and of themselves disabling. In several cases, the severity of the symptoms and the lack of social service support has resulted in ARC patients committing suicide. (3)

DEMONSTRATED NEED

Of the thirty-seven clients who have been given social service assistance by the Foundation, eight have fallen into the ARC category. Many other people with ARC have contacted the Foundation but failed to follow through when they found out that there was little that could be done for them. Personell at SFGH have referred four of the eight ARC clients to the Foundation and have indicated that the problem will probably grow as more 'pre-AIDS' patients are seen at the SFGH AIDS ward. At present, most ARC clients must rely on the county financed GA program since entry into SSI or SSDI programs is extremely difficult.

SUGGESTED ACTION

1. Develop a workable definition of ARC. The term is being used informally by many doctors, but efforts should be made to formalize this definition.
2. Once a workable definition has been developed, social service programs (especially SSI and SSDI) should be pressured to recognized ARC patients as disabled.



NEW YORK PHYSICIANS FOR HUMAN RIGHTS

Box 109 70 Greenwich Avenue
New York, New York 10011

December 1, 1983

Mr. Jay Lipner
95 Madison Avenue
New York, New York 10016

This statement was prepared by Drs. Peter A. Seitzman and Daniel C. William and represents the official position of New York Physicians for Human Rights.

It is clear that many or most AIDS patients have been disabled for long periods before serious opportunistic infections occur and allow clearcut diagnosis according to the current CDC criteria.

Physicians who have cared for many AIDS patients have recognized that certain clinical parameters are predictive of the development of AIDS as defined by the CDC.

Patients who fit this recognized profile of the prodrome of full-blown AIDS are currently denied disability benefits until they meet the CDC criteria.

Therefore NYPHR recommends that these patients should henceforth be diagnosed as having AIDS for purposes of disability determination if they meet the following criteria:

Disabling fatigue and oral thrush and one or more of the following signs, symptoms and laboratory findings: drenching night sweats, weight loss, fever, recurrent viral syndrome, diarrhea, herpes zoster, lymphadenopathy, splenomegaly, thrombocytopenia, leukopenia, lymphopenia, hypergammaglobulinemia, anemia, elevated beta-2-microglobulins, cutaneous anergy, elevated ESR and inverted helper/suppressor ratio.

Sincerely,

Leonard J. Rubin, MD
Secretary

TRANSMITTAL NO. 3
SSA Pub No. 68-0400402
February 28, 1984

Audience: DO/BO/TSC--CR, DRT, FR, OA,
OS, RR, SR, TSC-SR; PSC--CA, CRTA, DE,
IES, RECONR; ODO--CA, CATA, DE, DEC,
DIC, IS, RECON, RECONR; DIO--CA,
CATA, CDA, CIES, FDE, RECON, RECONR;
DDS--REF

Originating Office: SJH-44

PROGRAM OPERATIONS MANUAL SYSTEM
Part 04 - Disability Insurance
Chapter 004 - Case Development and Evaluation
Subchapter 02 - Disability Procedures

New Material	No. of Pages
DI E00402.255.....	1

ACTION NOTES

DI 00402.255A.--Cross-refer to
DI E00402.255.

Background

Data reveal that the allowance rate for acquired immune deficiency syndrome (AIDS) cases is extremely high (approximately 95 percent nationwide). Because of this high allowance rate, AIDS is now an exclusion to the deferred development procedures since this exclusion does not result in any significant loss of work-year savings, and permits payment of benefits as soon as a claim is allowed.

Explanation of Manual Changes

E00402.255 Exclusion from Deferral of Nondisability Development

This section indicates that in any claim with an allegation of AIDS, the district office must immediately initiate all nondisability development, including auxiliary claims.

Effective Date: Upon Receipt

**U.S. Department of
Health and Human Services
Social Security Administration
Office of Policy**
SSA Pub. No. 68-0400402
I.C.N. 991429

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form SSA-1296, "Request for Address or
Distribution Change", using the list number
on the address label.

E00402.255 Exclusion from Deferral of Nondisability Development

Data reveal that the allowance rate for acquired immune deficiency syndrome (AIDS) cases is extremely high (approximately 95 percent nationwide), and the mortality rate associated with this condition is also very high. Therefore, effective upon receipt of this transmittal, any claim with an allegation of AIDS, is an exclusion from the deferred development procedures. In these excluded claims, the district office must immediately initiate all nondisability development, including auxiliary claims. Since the likelihood of allowance is so great, this exclusion from the deferral procedures does not result in any significant loss of work-year savings and permits payment of benefits as soon as the claim is allowed.

SSA PROGRAM CIRCULAR



Disability Insurance



No 10-83-OD

Date: December 23, 1983

Division of Preadjudicative Policy, Office of Disability

Presumptive Disability/Blindness Decisions—Title XVI Claims

JAN 26 1984

REMINDER ITEMS

REHABILITATION SERVICES ADM

This program circular is being issued as a reminder item to highlight current Program Operations Manual System (POMS) instructions that deal with presumptive disability/blindness (PD/PB) decisions.

In recognition of the fact that in some disability or blindness cases additional time is needed to obtain and evaluate medical evidence, title XVI disability or blindness payments may be made for as many as 3 months prior to a formal disability determination provided the individual is found to be presumptively disabled or blind. Any such payments based on presumptive disability (PD) or presumptive blindness (PB) are not considered overpayments if it is later formally determined that the individual is not disabled or blind.

Since the title XVI program is based on need, it is important to make PD/PB decisions in appropriate cases. A PD or PB decision should be made in a case when the available evidence, though not sufficient for a final determination of disability or blindness, indicates a high degree of probability that the claimant is disabled or blind. Recent experience, indicates that DDS's may be underutilizing the PD/PB provision. In fiscal year (FY) 1979, 43,484 PD/PB decisions were made; in the first 3 quarters of FY 1983, only 8,103 PD/PB decisions were made.

Certain impairment categories require particular care. In September 1981, a POMS instruction (DI T2152.1) was issued to call attention to PD/PB decisions in areas with the greatest risk of reversal and to identify other areas where caution was necessary. The overall reversal rate decreased during the three quarters following issuance of the temporary instruction but has since increased again. This circular contains some important reminder items related to PD/PB decisions, the instructions for which are contained in POMS DI 2152.1 and T2152.1. These two sections warrant close review.

Social Security Administration
Office of Policy
SSA Pub. No. 64-044

Retention Date: May 1, 1984

Distribution: All Holders of
POMS Part 4

200-
next page

1. New Impairment Category--AIDS

Acquired immune deficiency syndrome (AIDS) is a newly identified impairment of national concern. Individuals with AIDS may be subject to pneumonic or disseminated opportunistic infection or diseases which are usually not seen in healthy individuals or which do not have disastrous effects in ostensibly healthy individuals. In individuals with AIDS, these opportunistic infections or diseases have been reported to have an exceedingly high mortality rate. DDS's should consider a finding of PD for AIDS cases when the evidence or information indicates that there is a high degree of probability that the PD finding will be confirmed when complete evidence is obtained.

2. Other Impairments Where Maximum PD Potential Should Be Used

It is important to make as many PD decisions as can be soundly made. Certain impairments have consistently proved reliable, and the DDS's should utilize the maximum PD potential in these areas. Examples of such impairments are:

- a. Mental deficiency;
- b. Neoplasms;
- c. Diseases of the central nervous system resulting in paralysis or motor dysfunction; and
- d. Chronic renal disease.

The DDS's should also be alert to the district office (DO) PD categories (DI 2152.6) and make every effort to identify any cases where the impairment falls into any of these categories but was overlooked by the DO.

3. Impairment Categories Where PD/PB Decisions Need Special Care

Experience has shown that PD/PB decisions in the following impairment categories have a high potential for reversal. Therefore, a careful approach in using PD/PB decisions should be applied to such impairments. However, when there is convincing evidence, PD/PB decisions should be made because the purpose of the PD/PB provision is to expedite benefits since these claimants have limited funds and assets.

a. Mental Impairments

PD decisions made on mental retardation cases have proven to be especially amenable to PD and are seldom reversed. PD decisions in other mental disorders categories should be made with special care because, in most cases, the background and history are essential for proper evaluation. PD's can be quickly made in some cases, of course, such as situations where there is striking evidence of prolonged severe psychosis or chronic brain syndrome.



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

July 7, 1983

MEMORANDUM TO: ALL SSA EMPLOYEES

SUBJECT: Concern about the Transmission of Acquired
Immune Deficiency Syndrome (AIDS)

The Social Security Administration has a well-deserved and long-established reputation for providing prompt, efficient, and compassionate service to the American people. I know this to be true from my own personal experience as a Congresswoman. It was, therefore, a shock and a personal disappointment to learn that a few Social Security employees, because of unfounded fears about their health, are concerned about interviewing individuals with AIDS, or even unwilling to process papers provided by AIDS victims.

Dr. Edward Brandt, Assistant Secretary for Health, speaks for both science and the medical profession when he tells us and the American people that:

"There is no risk from casual contact, and certainly no risk from handling papers touched by victims of this horrible disease. Indeed, interviewing patients presents no risk to the interviewer. Let me again emphasize that there has been no transmission from patients to physicians or other health workers."

I ask each of you to read Dr. Brandt's short, straightforward statement. I expect every employee to perform in the best tradition of the Social Security Administration by providing full service to our public, including AIDS victims, who need our help and compassion. I want you to know that I have personally met with AIDS victims and assured them that this Department would stand with them--that we will service their needs and rights.

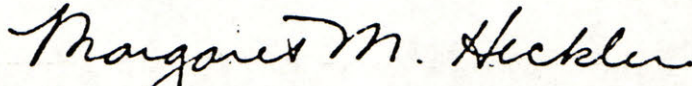
Page 2 - All SSA Employees

A copy of this memorandum and the attachment have been sent to AFGE and NFFE.

Half a century ago, one of history's and our country's wisest Judges (Louis Brandeis of the United States Supreme Court) put into simple words what no government official--high or low--should ever forget:

"Our government . . . teaches the whole people by its example."

I ask each of you to join me and your fellow employees in setting an example that demonstrates the compassion of our government.


Margaret M. Heckler
Secretary

Attachment

Office of the Assistant Secretary
for Health
Washington DC 20201

Date : June 22, 1983
FROM : Assistant Secretary for Health
SUBJECT: Concern About the Transmission of Acquired Immune
Deficiency Syndrome
TO : The Secretary of Health and Human Services

This is in response to recent information that SSA personnel are concerned about, and have even refused, to interview patients with Acquired Immune Deficiency Syndrome (AIDS) or even to handle paperwork generated by them. There is no cause for such concern, fear or refusal. AIDS is transmitted only by sexual contact, contaminated needles or the use of blood or blood products. There is no risk from casual contact, and certainly no risk from handling papers touched by victims of this horrible disease. Indeed, interviewing patients presents no risk to the interviewer. Let me again emphasize that there has been no transmission from patients to physicians or other health workers.

This situation must be corrected. There is no scientific basis for this refusal of SSA employees to carry out their assigned duties.

I will be happy to discuss this with you, and I would urge you to take the steps necessary to see that these AIDS victims are not denied their opportunity to apply for disability benefits.

Thank you very much.



Edward N. Brandt, Jr., M.D.

TRANSMITTAL NO. 81
SSA Pub. No. 68-0400200
July 15, 1983

Audience: DCE, DE, DEC, REONE,
QAEX, OATR

Originating Office: SJH-41

PROGRAM OPERATIONS MANUAL SYSTEM
Part 4--Disability Insurance
Chapter 2--Development and Evaluation

New Material	No. of Pages	Discard	No. of Pages
Table of Contents (E2200-E2899).....	1	Table of Contents (E2800-2899).....	1
DI E2200 B. - DI E2200 C.....	2	-----	

Background

This transmittal replaces Instructional Teletype 114-83 and conveys instructions to be used in the evaluation of acquired immune deficiency syndrome (AIDS) for disability purposes. AIDS is a newly identified syndrome of national magnitude. Due to the increasing incidence and the high mortality rate, there is an immediate need to issue evaluation guidelines.

Explanation of Manual Changes

E2200 Evaluation of Acquired Immune Deficiency Syndrome

This section provides instructions for the evaluation of disability in acquired immune syndrome cases.

ACTION NOTES

DI 2502.--Add after item 16. and before the NOTE: "17. Acquired Immune Deficiency Syndrome. The diary should be established for 1 year from the date of adjudication."

U.S. Department of
Health and Human Services
Social Security Administration
Office of Operational Policy and Procedures
SSA Pub. No. 68-0400200
I.C.N. 990811

Effective Date: Upon Receipt

Distributed on list 244

To adjust quantity requirements, submit form SSA-1298, "Request for Address or Distribution Change", using the list number on the address label.

E2200 Evaluation of Acquired Immune Deficiency Syndrome

A. General

Acquired immune deficiency syndrome (AIDS) consists of a diffuse set of symptoms and signs of, as yet, unknown etiology. Individuals with AIDS may be subject to pneumonic or disseminated opportunistic infection or diseases which are usually not seen in healthy individuals or which do not have disastrous effects in ostensibly healthy individuals. In individuals with AIDS, these opportunistic infections or diseases have been reported to have an exceedingly high mortality rate.

B. Commonly Reported Opportunistic Infections or Diseases

The most commonly reported opportunistic infections or diseases are *Pneumocystis carinii* pneumonia and Kaposi's sarcoma. Among the others reported are:

1. Pneumonia, Meningitis, or Encephalitis due to--
 - a. Aspergillosis
 - b. Candidiasis
 - c. Cryptococcosis
 - d. Cytomegalovirus
 - e. Nocardiasis
 - f. Strongyloidosis
 - g. Toxoplasmosis
 - h. Zygomycosis
 - i. Atypical Mycobacteriosis;
2. Esophagitis due to--
 - a. Candidiasis
 - b. Cytomegalovirus
 - c. Herpes simplex
3. Progressive multifocal leukoencephalopathy
4. Chronic enterocolitis due to cryptosporidiosis
5. Extensive mucocutaneous herpes simplex of more than 5 weeks duration.

C. Evaluation of AIDS

Because of the reported high mortality, an individual with a documented pneumonic or disseminated opportunistic infection or disease should be found to be under a disability on the basis of the requirement of regulations 404.1505(a) and 416.905(a) defining disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. In the evaluation of AIDS, the important aspect of this definition is "expected to result in death." The impairment will be found to meet any applicable listed impairment (e.g., Listing 13.04 for Kaposi's sarcoma) or to be medically equivalent to a listed impairment (usually included in Listing 13.01). The documentation of these opportunistic infections or of Kaposi's sarcoma requires adequate description of the clinical findings and information providing the results of microbiologic cultures or tissue biopsy.

The onset of the disabling impairment will be considered to be the date medical findings demonstrated the pneumonic or disseminated opportunistic infection or disease. An earlier onset date of disability may be established if this is dictated by the documented medical findings in the case. These findings must include medical reports showing treatment for a severe illness considered to represent a disabling impairment.

A medical reexamination diary should be set for 1 year from the date of adjudication.

E. Routing of Case Material

A photocopy of the case material for AIDS cases, which are allowed or denied, should be sent to Herbert L. Blumenfeld, M.D., Room 2400 Dickinson Building, 1500 Woodlawn Drive, Baltimore, Maryland 21241.

New York State
Department of Social Services
Office of Disability Determinations
110 William Street
New York, NY 10038

To: Distribution E

Date: May 31, 1983

From: Alan Seckular

Subject: Evaluation of Acquired
Immune Deficiency Syndrome
(AIDS)

Action Note: This release supercedes DD-519 dated 2/23/83.

Acquired Immune Deficiency Syndrome (AIDS) which manifests itself among many groups (including homosexuals, drug addicts, Haitians, hemophiliacs, and infants) consists of a diffuse set of signs and symptoms. Etiology is yet unknown. Early diagnosis may be difficult and uncertain. Manifestations may be as vague as weight loss or lassitude, and minimal dysfunction may be present, even in individuals in whom some immunological impairment has been demonstrated.

Individuals with AIDS may be subject to pneumonic or disseminated opportunistic infection or diseases which are usually not seen in healthy individuals or which do not have disastrous effects in ostensibly healthy individuals. However, in individuals with AIDS, these opportunistic infections or diseases have been reported to have an exceedingly high mortality rate. Cases should be evaluated at least 6 months after the onset of clinical findings, unless an opportunistic disease or infection is present which may be allowed under the criteria in Section C. Consideration as to whether a presumptive disability determination (PD) is appropriate should be made in Title XVI cases. For example, a claimant alleging AIDS who is currently hospitalized for pneumonia could be placed under a PD while medical evidence is developed.

- A. The most commonly reported opportunistic infections or diseases are *Pneumocystis carinii* pneumonia and Kaposi's sarcoma.
- B. Among others reported are:
1. Pneumonia, meningitis or encephalitis due to:

aspergillosis	nocardiasis
candidiasis	strongyloidosis
cryptococcosis	toxoplasmosis
cytomegalovirus	zygomycosis
atypical mycobacteriosis	
 2. Esophagitis due to:

candidiasis
cytomegalovirus
herpes simplex
 3. Progressive multifocal leukoencephalopathy.
 4. Chronic enterocolitis due to cryptosporidiosis.
 5. Extensive mucocutaneous herpes simplex of more than 5 weeks duration.

C. Evaluation of these cases should proceed as follows:

1. The results of any diagnostic tests done must be obtained. The most common laboratory abnormalities found in this syndrome are:
 - a. Anergy on skin testing with common antigens
 - b. Low WBC
 - c. Absolute lymphocyte counts
 - d. Persistent (3 months) inversion of the "helper" (OKT 4) T-cells to "suppressor" (OKT 8) T-cells ratio caused by decreased numbers of the former (normal is greater than 1.0).
 - e. Diminished lymphocyte responses to stimulation by antigens or mitogens.
 - f. Open-lung or skin biopsy (if performed).
2. Due to the reported high mortality, an individual with a documented pneumonic or disseminated opportunistic infection or disease should be found under a disability. The impairment will be found to meet any applicable listed impairment or to "equal" a listed impairment (e.g., 3.09B, 7.15B, 13.03A, 13.06A, or 110.09A (children only)). An "equals" determination requires a rationale. Onset of the impairment will be considered to be the onset of the pneumonic or disseminated opportunistic infection or disease; OR, if medical evidence documents earlier findings of a severe illness such as persistent high fever and weight loss, an earlier onset may be established. Diagnosis is Acquired Immune Deficiency Syndrome followed by any other disease in parentheses (e.g., AIDS (Kaposi's sarcoma)) and is coded 2791. A medical re-examination diary should be set for one year from the date of adjudication.
3. Due to the episodic nature of the overt manifestations of the illness, it may be necessary to defer development of cases in which a pneumonic or disseminated opportunistic infection or disease is not present. Each case should be evaluated by the guidelines in POMS DI 2021.D.4.
4. All denial or cessation decisions must be countersigned in the Remarks section (Item 34 of the SSA-331) by the Regional Administrator. A case diagnosed as AIDS with a documented opportunistic disease would never be a denial.
5. For all determinations, have 2 photocopies of the case material made including the SSA-3368 or 3820, all medical evidence, and SSA-831/834. Send one photocopied packet to Alan Seckular, Program Policy & Planning, 13th Floor. Staple the 2nd copy together with an SSA-408 routing slip addressed to:

Herbert L. Blumenfeld, M.D.
Room 2400 Dickinson Building
1500 Woodlawn Drive
Baltimore, Maryland 21241

 - a. Instruct the module typist to prepare a mailing label as above.
 - b. Insert the photocopied material loosely in the file prior to medical review.
 - c. The Technical Reviewer will check to see that this photocopied packet is in all cases in which a diagnosis of Acquired Immune Deficiency Syndrome (AIDS) is made (Item 17 of SSA-231).
 - d. The Clearance Clerk will remove the packet for mailing when clearing the case.

SSA Teleclaims Application Filing Procedure for
A.I.D.S. Victims

In order to alleviate the need for A.I.D.S. victims to travel in to a Social Security Office, sometimes wait to be interviewed and possibly be exposed to the illnesses of other disabled claimants and the general public in the Social Security Office A.I.D.S. Victims may call the appropriate telephone number on the enclosed list to file a "Teleclaim" for Social Security and/or Supplemental Security income disability benefit(s).

For those victims who live in the Metropolitan NYC area refer to page 5 which lists the TSC's (Teleservice Centers) Telephone Numbers. SSA Employees at those numbers will not conduct the claims interviews. Instead, they will ask the A.I.D.S. victim (or the person calling on his/her behalf) for the name, address, social security and telephone numbers of the victim. The SSA employee will then call an official of the Local SSA Office with that information. A call will then be made to complete the necessary application forms, generally within two work days.

For all other areas outside of the metro area, refer to the other telephone listings on pages 1-5. In this case, the SSA employee that is reached at those numbers will generally conduct the teleclaims interview at that time, or call back at a specified time.

The Aides victim or the person assisting him/her should be prepared to supply the following information to the SSA interviewer:

- Date of Birth
- Date Victim first developed symptoms
- Date he/she had to stop working
- Names and Addresses of Medical Treating Sources
- Dates of Medical Treatment
- Employment history
- Income and Assets Information (if filing for SSI)

It is important to remember that the numbers on the enclosed pages are only for the filing of claims and not for general information. Please use the numbers listed in the Local Telephone Directories to obtain general information.

AIDS REPORT

The Medical Consultant Staff of the Office of Disability has reviewed material on 597 AIDS claims cumulatively through January 5, 1984. Ninety-five (95) percent of these claims (564/597) were allowed.

	<u>Allow</u>	<u>Deny</u>
Alabama	2	1
Arizona	1	0
California	153	12
Colorado	10	0
Connecticut	8	0
Delaware	1	0
District of Columbia	3	0
Florida	44	3
Georgia	4	0
Illinois	2	1
Indiana	0	1
Iowa	1	0
Kansas	2	0
Kentucky	4	0
Louisiana	2	0
Maine	3	0
Maryland	5	1
Massachusetts	9	0
Michigan	3	2
Minnesota	1	0
Missouri	3	0
Nebraska	1	0
Nevada	2	0
New Hampshire	2	0
New Jersey	13	1
New York	242	4
North Carolina	4	0
Ohio	2	0
Oklahoma	0	0
Oregon	0	1
Pennsylvania	8	1
Puerto Rico	1	0
Rhode Island	2	0
South Carolina	4	0
Tennessee	1	2
Texas	16	2
Utah	1	0
Virginia	2	1
Washington	2	0
Totals	<u>564</u>	<u>33</u>

State Code-04**ARKANSAS-AR (Cont'd)****Dallas REGION-61**

Office Code	Zip Code	Class	Address	Adm. Comm.	FTS
A68	72143	B-12	SEARCY (Little Rock), 401 W. Vine, P.O. Box 369	501-268-5601	740-5011*
704	72301	B-12	WEST MEMPHIS (Forrest City), 304 N. 6th, P.O. Box 2168	501-735-7772	222-3011

OUT-OF-STATE SERVICING OFFICE

Texarkana, Texas

State Code-05**CALIFORNIA-CA****San Francisco REGION-91**

D46	91801	B-12	ALHAMBRA (Pasadena), Suite 101, 600 W. Main St.	213-570-8321	213-570-8321
249	92806	I	ANAHEIM, 1070 N. State College Blvd., P.O. Box 6440	714-776-0361	799-2257
D35	95603	B-12	AUBURN (Citrus Heights), 375 Nevada St.	916-885-3741	916-885-3741
**BAKERSFIELD					
963	93303	II	DOWNTOWN, 1414 Truxtun Ave., P.O. Box 2619	805-861-4305	984-1305
563	93307	M-12	SOUTHEAST (Downtown), 810 E. California Ave.	805-861-4311	984-1318
B73	92220	B-12	BANNING (Riverside), 1184 W. Ramsey St., P.O. Box 937	714-849-4708	714-849-4708
D88	90266	B-12	BEACH CITIES, (Torrance), Suite 104, 500 S. Sepulveda Blvd., Manhattan Beach, CA	213-376-3497	213-376-3497
B59	90706	B-12	BELLFLOWER (Long Beach), 10135 E. Artesia Blvd.	213-866-8237	213-866-8237
**BERKELEY					
976	94704	I	BERKELEY, 1950 University Ave.	415-486-3873	415-449-3873
D45	94710	B-12	SOUTHWEST (Berkeley), 931 Ashby Ave.	415-486-3884	449-3884
A77	91503	B-12	BURBANK (Glendale), 129 S. Golden Mall, P.O. Box 4270	213-846-4089	213-846-4089
D38	95009	B-12	CAMPBELL (San Jose D/T), 770 W. Hamilton Ave., P.O. Box 727	408-275-7743	463-7743
062	91304	I	CANOGA PARK, 21200 Roscoe Blvd.	213-883-7336	796-3352
067	93923	B-12	CARMEL (Salinas), Suite 201, 3785 Via Nona Marie	408-625-3985	408-625-3985
979	95926	II	CHICO, 2nd Fl., 555 Rio Lindo Ave., P.O. Box 2208	916-345-5140	916-345-5140
E77	95610	II	CITRUS HEIGHTS, Suite 2800, 6060 Sunrise Vista, P.O. Box 196	916-726-8194	916-726-8194
434	90224	B-12	COMPTON (Torrance), 2221 E. Rosecrans Blvd., P.O. Box 6075	213-637-7538	213-637-7386
B70	91720	B-12	CORONA (Riverside), 1047 W. 6th St., Suite D	714-734-2100	714-734-2100
D37	92626	B-12	COSTA MESA (Santa Ana), Suite 108, 1525 Mesa Verde Dr., E.	714-979-1374	714-979-1374
B64	90230	B-12	CULVER CITY (L.A. Westwood), Suite 140, 5601 W. Slauson Ave.	213-670-8342	213-670-8342
A88	94015	B-12	DALY CITY (San Mateo), 3 Fl., 350 90th St.	415-994-3020	415-994-3020
942	93215	B-12	DELANO (Bakersfield D/T), 1619 Main St.	805-725-3720	805-725-3720
D94	90242	B-12	DOWNEY (Huntington Park), 9045 E. Imperial Highway	213-869-6730	213-869-6730
250	92022	II	EL CAJON, 570 N. 2nd St., P.O. Box 1626	619-440-1150	619-440-1150
985	92243	II	EL CENTRO, 1699A W. Main St.	619-352-4961	894-2456
384	91734	M-12	EL MONTE (Pasadena), 11026 E. Valley Mall, P.O. Box 5570	213-575-2818	213-575-2818
931	92025	II	ESCONDIDO, 525 N. Andreason	619-745-2201	619-745-2201
956	95501	II	EUREKA, 215 4th St., P.O. Box 4450	707-443-9341	707-443-7341
D47	94533	B-12	FAIRFIELD (Vallejo), 2 Fl., 1125 Missouri St., P.O. Box 2300	707-425-0632	707-425-0632
B69	92335	B-12	FONTANA (San Bernardino), 9811 Sierra Ave., P.O. Drawer G	714-823-3466	714-823-3466
B60	94538	B-12	FREMONT (Hayward), 39176 State St.	415-797-0301	415-797-0301
**FRESNO					
E07	93721	M-12	FRESNO (Downtown), Room 1001, Federal Bldg., 1130 'O' St.	209-487-5448	467-5448

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 *Operator Assistance call. Ask for local number.

Office Code	Zip Code	Class	Address	Adm. Comm.	FTS
**FRESNO (Continued)					
952	93795	I	FRESNO, 5090 N. West Ave., P.O. Box 9900	209-487-5020	467-5020
E08	93727	M-12	SOUTHEAST Fresno, 5171 E. Kings Canyon Rd.	209-487	467-5545
386	93776	M-12	WEST (Fresno), 848 California Ave., P.O. Box 12027	209-487-5469	467-5469
D39	92632	B-12	FULLERTON (Anaheim), 140 E. Commonwealth Ave., P.O. 300	714-879-0640	714-879-6011*
D36	92640	B-12	GARDEN GROVE (Santa Ana), 10540 Chapman Ave.	714-636-7378	714-636-7378
561	95020	B-12	GILROY (San Jose D/T), 8120 Westwood Dr., P.O. Box 1448	408-842-7101	408-842-7101
965	91209	I	GLENDALE, 318 W. Wilson Ave., P.O. Box 449	213-240-8590	798-2730
E31	91740	B-12	GLENDORA (Pomona), 405 Alosta Ave., P.O. Box 1500	213-963-8441	213-963-8441
B65	93232	B-12	HANFORD (Visalia), 400 E. 6th St., P.O. Box 188	209-582-5410	209-582-5410
066	94543	II	HAYWARD, Suite D, 22941 Atherton St., P.O. Box 0805	415-582-9300	415-783-4291
906	92343	B-12	HEMET (Riverside), 105 N. Girard, P.O. Box 918	714-925-3312	714-925-3312
968	90028	I	HOLLYWOOD, 6730 Sunset Blvd., P.O. Box 1391	213-468-3188	793-3188
A78	92646	B-12	HUNTINGTON BEACH (Santa Ana), 8851 Adams Ave.	714-964-7658	714-964-7658
966	90255	I	HUNTINGTON PARK, 6303 Rugby Ave., P.O. Box 2468	213-583-5277	798-4735
E39	92201	B-12	INDIO (Palm Springs), 45-570 Grace St.	619-347-3230	714-347-3230
971	90301	I	INGLEWOOD, 230 E. Spruce Ave., P.O. Box 29	213-642-5930	966-5930
B71	91214	B-12	LA CRESCENTA (Glendale), 3043 Foothill Blvd.	213-248-2709	213-248-2709
B80	92041	B-12	LA MESA (El Cajon), 7373 University Ave., P.O. Box 231	619-464-1634	619-464-1634
E30	91744	B-12	LA PUENTE VALLEY (Pomona), 16030 E. Amar Rd., P.O. Box 3547, City of Industry, CA	213-968-6816	213-968-6816
059	93535	II	LANCASTER, 311 E. Ave. K-4	805-948-5903	805-948-5903
B66	94550	B-12	LIVERMORE (Hayward), 1424 Concannon Blvd., P.O. Box 5006	415-455-5526	415-455-5526
B74	95241	B-12	LODI (Stockton), 318 S. Crescent Ave., P.O. Box 796	209-369-1944	209-369-1944
958	90813	I	LONG BEACH, 1320 Atlantic Ave.	213-591-4467	213-591-4467
**LOS ANGELES					
951	90017	I	DOWNTOWN, 841 S. Figueroa St.	213-688-4345	798-4344
253	90007	II	UNIVERSITY VILLAGE (Huntington Park), 3375 S. Hoover, P.O. Box 77911	213-747-6043	798-5637
026	90016	M-12	CRENSHAW (Inglewood), 3657 Crenshaw Blvd., P.O. Box 56000	213-688-6155	798-6155
904	90033	M-12	BOYLE HEIGHTS (Monterey Park), 240 N. Breed St.	213-265-0737	793-9737
905	90032	B-12	EL SERENO (Monterey Park), 5411 W. Valley Blvd.	213-221-1633	213-221-1633
D42	90036	B-12	MIRACLE MILE (Hollywood), 641 S. La Brea Ave.	213-938-2815	213-688-2000
064	90002	II	WATTS, 10345 S. Central Ave.	213-564-7212	798-4927
970	90024	I	WESTWOOD, Suite 10203, 11000 Wilshire Blvd., P.O. Box 24058	213-824-7950	799-7931
D44	90010	B-12	WILSHIRE CENTER (Hollywood), 3836 Wilshire Blvd.	213-739-0519	213-739-0519
947	93639	B-12	MADERA (Fresno), 424 N. Gateway Dr., P.O. Box 1287	209-673-9101	209-673-9101
A86	90292	B-12	MARINA VENICE (L.A. Westwood), 4656 Admiralty Way, Marina Del Rey, CA	213-823-1723	213-823-1723
989	95901	II	MARYSVILLE, 302 F St., P.O. Box 791	916-743-1833	916-743-1833
060	95340	B-12	MERCED (Modesto), 3191 M St., P.O. Box 2225	209-723-0494	209-723-0494
978	95353	II	MODESTO 1230 12th St., P.O. Box 3311	209-523-2666	209-523-2666
B72	91016	B-12	MONROVIA (Pasadena), 601 S. Myrtle St.	213-359-1415	213-359-1415
063	91754	I	MONTEREY PARK, 861 S. Atlantic Blvd.	213-283-0591	798-6687
A79	94589	B-12	NAPA (Vallejo), Suite 212, 1700 2nd St.	707-252-1640	707-252-1640
A80	91606	B-12	NORTH HOLLYWOOD (Van Nuys), 11024 Victory Blvd., P.O. Box 3898	213-985-4512	213-985-4517
562	90650	M-12	NORWALK (Whittier), 12311 E. Firestone Blvd.	213-868-0595	213-868-0595

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Office Code	Zip Code	Class	Address	Adm. Comm.	FTS
**OAKLAND					
953	94612	I	DOWNTOWN, 427 13th St.	415-273-6054	536-6054
028	94605	M-12	EAST (Downtown), Bldg 13, Foothill Sq., 10700 MacArthur Blvd.	415-273-7921	536-7494
564	94607	M-12	WEST (Downtown), 1133 7th St.	415-273-7819	536-7819
987	92054	II	OCEANSIDE, 125 S. Tremont St., P.O. Box 1039	714-722-1338	714-722-1338
E27	95965	B-12	OROVILLE (Chico), 1500 Lincoln St.	916-534-1700	916-534-1700
B67	93030	B-12	OXNARD (Ventura), 327 N. 5th St., P.O. Box 1107	805-486-6121	805-486-7395
070	92262	II	PALM SPRINGS, 977 Tahquitz-McCallum Way	619-325-5381	714-325-8313
065	94306	B-12	PALO ALTO (San Jose D/T), 400 Cambridge Ave., P.O. Box 11426	415-325-6707	415-325-6707
957	91106	I	PASADENA, 104 N. Mentor St.	213-796-0077	799-0337
B63	94565	B-12	PITTSBURG (Walnut Creek), 340 Black Diamond St., P.O. Box 1639	415-439-1025	415-439-1025
E78	95667	B-12	PLACERVILLE (Citrus Heights), 550 Main St., P.O. Box 1507	916-626-8421	916-626-8421
981	91769	I	POMONA, 445 E. Holt Ave., P.O. Box 2326	714-622-5296	714-622-5296
944	93257	B-12	PORTERVILLE (Visalia), 262 N. 2nd St.	209-781-4022	209-781-4021
969	96099	II	REDDING, 1555 East St., P.O. Box 1938	916-450-5277	450-5425
B61	92373	B-12	REDLANDS (San Bernardino), Suite S, 461 Tennessee St., P.O. Box 1452	714-793-8229	714-793-8229
D34	94063	B-12	REDWOOD CITY (San Mateo), Suite 200, 411 Middlefield Rd., P.O. Box 8009	415-364-1925	415-364-1925
383	94801	B-12	RICHMOND (Berkeley), 325 Harbour Way, P.O. Box 1632	415-235-7050	415-235-7050
251	92507	I	RIVERSIDE, 1860 Chicago Ave., P.O. Box 5977	714-351-6590	796-6590
A84	95661	B-12	ROSEVILLE (Citrus Heights), Suite O, 212 Harding Blvd., P.O. Box 1169	916-783-9143	916-783-9143
**SACRAMENTO					
955	95802	I	DOWNTOWN, 1501 L St., P.O. Box 431	916-440-3271	448-3271
E28	95825	B-12	NORTH (Sacramento D/T), Suite 390, 220 Hurley Way, P.O. Box 255099	916-484-4681	468-4681
E79	95823	III	SOUTH, 2251 Florin Rd., P.O. Box C-9506	916-440-2431	448-2128
984	93901	II	SALINAS, Rm. 201, 344 Salinas St.	408-443-2187	468-2187
959	92402	I	SAN BERNARDINO, 550 W. 4th St., P.O. Box 1550	714-383-5805	793-5550
**SAN DIEGO					
436	92011	II	CHULA VISTA, Suite 105, Bldg. 2, 336 Oxford St.	619-427-4081	619-427-4081
D41	92111	B-12	LINDA VISTA (San Diego), 4344 Convoy St.	619-560-9710	619-560-9710
954	92138	I	SAN DIEGO, P.O. Box 82727, 880 Front St.	619-293-5808	895-5322
D43	92109	B-12	PACIFIC BEACH (San Diego), Suite 2F, 4501 Mission Bay Dr.	619-483-5002	619-270-4563
435	92114	M-12	SOUTHEAST (San Diego), 415 N. Euclid St.	619-293-5980	895-6699
027	91340	B-12	SAN FERNANDO (Van Nuys), 120 N. Maclay Ave.	213-365-2561	796-3337
**SAN FRANCISCO					
252	94108	M-12	CHINATOWN (Sutter Street), 560 Kearney St.	415-556-0165	556-1684
029	94124	M-12	HUNTER'S POINT (Mission), 5815 3rd St.	415-556-0160	556-0160
781	94110	II	MISSION, 2601 Mission St.	415-556-9471	556-9471
782	94112	B-12	OUTER MISSION (Mission), 4377 Mission St.	415-556-1935	556-1935
977	94116	B-12	PARKSIDE (Mission), 2311 Taraval St.	415-556-4880	556-4880
950	94109	I	SUTTER STREET, 1355 Sutter St.	415-556-9246	556-9231
433	94115	M-12	WESTERN ADDITION (Sutter Street), Japan Ctr. - West Bldg., 1825 Post St.	415-556-8000	556-8007
**SAN JOSE					
960	95113	I	DOWNTOWN, Suite 910, 111 N. Market St.	408-275-7571	463-7571
385	95116	M-12	EAST (San Jose D/T), 3139 Story Rd., P.O. Box 3172	408-275-7617	463-7679
E41	95123	B-12	SOUTH (San Jose D/T), 5750 Santa Teresa Blvd.	408-275-7278	463-7278

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*Operator Assistance call. Ask for local number.

State Code-05**CALIFORNIA-CA (Cont'd)****San Francisco REGION-91**

Office Code	Zip Code	Class	Address	Adm. Comm.	FTS
B58	92675	B-12	SAN JUAN CAPISTRANO (Santa Ana), 32124 Paseo Adelanto	714-493-3070	714-493-3070
D48	94577	B-12	SAN LEANDRO (Oakland D/T), Room 212, 151 Callan Ave.	415-483-0231	415-483-0231
986	93401	II	SAN LUIS OBISPO, 1595 Los Osos Valley Rd.	805-544-6411	805-544-6411
967	94403	I	SAN MATEO, Building C, 2121 El Camino Real	415-341-6569	470-9054
E40	94806	B-12	SAN PABLO (Berkeley), 2101 Van Ness St., P.O. Box 267	415-234-0314	415-234-2438
A82	90733	B-12	SAN PEDRO (Long Beach), 210 N. Pacific Ave., P.O. Box 5363	213-548-2694	796-2694
988	94915	II	SAN RAFAEL, Suite 800, 1000 4th St., P.O. Box 150	415-453-1242	415-453-1242
972	92712	I	SANTA ANA, 34 Civic Ctr. Plz., P.O. Box C-12670	714-836-2968	799-2968
961	93101	II	SANTA BARBARA, 911 Olive St.	805-966-4686	960-6201
061	95061	II	SANTA CRUZ, 175 Walnut Ave., P.O. Box 1355	408-426-7505	408-426-7505
068	93454	B-12	SANTA MARIA (San Luis Obispo), 135 W. Carmen Lane	805-925-2485	805-925-2485
964	95402	II	SANTA ROSA, 2300 Mendocino Ave., P.O. Box 1769	707-525-4251	450-4341
962	95201	I	STOCKTON, 826 N. California St., P.O. Box 607	209-946-6215	463-6215
A83	94086	B-12	SUNNYVALE (San Jose D/T), Suite B, 1214 Oakmead Pkwy.	408-275-7559	463-7559
983	90509	I	TORRANCE, 1321 Post Ave., P.O. Box 2988	213-328-8081	798-3753
A85	95482	B-12	UKIAH (Santa Rosa), 285 Orchard	707-462-1588	707-462-1588
973	94590	II	VALLEJO, 823 Marin St., P.O. Box 1768	707-643-2312	707-643-2312
975	91401	I	VAN NUYS, 6501 Van Nuys Blvd.	213-997-3014	796-3014
974	93003	II	VENTURA, Suite 101, 3585 Maple St., P.O. Box 3538	805-642-2068	805-642-2068
A87	92392	B-12	VICTORVILLE (San Bernardino), 14425 7th St., P.O. Box 1349	619-245-1750	619-245-1750
980	93277	II	VISALIA, 505 N. Court St.	209-734-6751	209-734-6751
248	94596	II	WALNUT CREEK, 1942 Mt. Diablo Blvd., P.O. Box 5306	415-938-4000	415-938-4000
948	95077	B-12	WATSONVILLE (Santa Cruz), 30 E. 5th St., P.O. Box 551	408-722-7141	408-722-7144
943	91791	B-12	WEST COVINA (Pomona), 2934 E. Garvey S.	213-966-3594	213-966-3594
E29	95691	B-12	WEST SACRAMENTO (Sacramento D/T), 1205 Merkley Ave.	916-440-2551	448-2551
982	90608	I	WHITTIER, 7227 S. Greenleaf Ave.	213-693-4784	213-693-4784

OUT-OF-STATE SERVICING OFFICE

Reno, Nevada
Yuma, Arizona

State Code-06**COLORADO-CO****Denver REGION-81**

Office Code	Zip Code	Class	Address	Adm. Comm.	FTS
888	81101	B-12	ALAMOSA (Durango), 517 Main St., P.O. Box 119	303-589-3004	303-589-3004
D24	80010	B-12	AURORA (Denver D/T), 9801 E. Colfax Ave.	303-837-6151	327-6151
889	80302	B-12	BOULDER (Denver D/T), Suite 105, 1900 Folsom St., P.O. Box 9557	303-440-0781	303-440-0781
D29	81212	B-12	CANON CITY (Pueblo), 502 Royal Gorge Blvd., P.O. Box 1105	303-275-8510	303-275-8510
887	80901	II	COLORADO SPRINGS, 25 N. Spruce St., P.O. Box 30	303-473-5290	323-2253
			**DENVER		
882	80203	I	DOWNTOWN, 5th Fl, Columbine Bldg., 1845 Sherman St.	303-837-2786	327-2786
382	80219	B-12	SOUTHWEST (Denver D/T), 2525 W. Alameda, P.O. Box 19520	303-837-5070	327-5070
890	81301	II	DURANGO, 701 Camino Del Rio., P.O. Box 3457	303-247-3128	303-247-3128
092	80150	B-12	ENGLEWOOD (Denver D/T), Suite 100, 750 W. Hampden, P.O. Box 1617	303-837-2910	327-2910

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*Operator Assistance call. Ask for local number.

*Disability Determination Service Administration - 030
 P.O. Box 11980
 Phoenix, Arizona 85061
 3120 W. Clarendon
 Phoenix, Az. 85061
 FTS/Com: 602-264-2644
 William R. Sims, Administrator

Disability Determination Service Administration - 031
 P.O. Box 40060
 Tucson, Az. 85717
 3655 E. Second St., Suite 105
 Tucson, Az. 85716
 FTS/Com: 602-881-7330
 Pierrette Berard, Operations Manager

California (Decentralized)

Division of Disability Evaluation- 050
 744 " P " Street , Room 1750
 Sacramento , California 95814
 FTS/COM: 916-322-0771
 Gary G. Adams , Deputy Director
 Gary Middleton (916) 323-8664 Program Approval Analyst

Oakland - 051

Division of Disability Evaluation - 051
 P.O. Box 25225
 Oakland, California 94623
 124 Grand Ave.
 Oakland, Ca. 94621
 FTS/Com: 415-464-4016
 Michael A. Florenza, Branch Chief

Los Angeles East - 052

Division of Disability Evaluation
 P.O. Box 3819, Terminal Annex
 Los Angeles, Ca. 90051
 2404 Wilshire Blvd.
 Los Angeles, Ca. 90057
 FTS/Com: 213-739-3406
 Albert Ray, Branch Chief

San Diego - 053

Division of Disability Evaluation
 P.O. Box 81326
 6160 Mission Gorge Rd.
 San Diego, California 92120
 FTS/Com: 619-584-3372
 Bennett W Cox, Branch Chief
 Sacramento - 054

Division of Disability Evaluation
 P.O. Box 1827
 2016 21st Street
 Sacramento, California 95818
 FTS/Com: 916-939-2563
 Ronald Harmon, Branch Chief

Fresno - 055

Division of Disability Evaluation
 P.O. Box 1072
 1625 E. Shaw Avenue, Bldg. F
 Fresno, California 93710
 FTS/Com: 209-226-7000
 Patrick Peterson, Branch Chief

California (cont)

Los Angeles West - 056

Division of Disability Evaluation
P.O. Box 60999, Terminal Annex
5757 Wilshire Blvd.
Los Angeles, California 90036
FTS/Com: 213-857-6713
Jacqueline Smallcomb, Branch Chief

Guam - 650

Division of VR, Dept. of Education
GCIC Bldg., Ninth Floor
414 E. Soledad Avenue
Agana, Guam 96910
Com: 199-011-671-472-8806
Ben Mesa, Case Worker Supervisor

Northern Mariana Islands - 640

Disability Insurance-SSA
238 O'Hara St.
Agana, Guam 96910
Com: 199-011-671-471-7237
Don Wilson, Disability Examiner

Hawaii - 120

Disability Determination Branch
P.O. Box 2458
1580 Makaloa St., Suite 660
Honolulu, Hawaii 96814
FTS/Com: 808-944-8755
Helen Kawashima, Acting Branch Admin.

Nevada - 290

Bureau of Disability Adjudication
505 E. King Street, Rm. 403
Capitol Complex
Carson City, Nevada 89701
Com: 702-885-4430
FTS: 470-4911 (Ask for Commerical No.)
Daniel A. Mooney, Chief

FEDERAL FUNDING AND AIDS: FACTS AND STRATEGY

Research Funding: The principal goals of federal funding have been to track the incidence of AIDS, to determine its cause, and to develop effective diagnostic and treatment procedures. The receptivity of Congress, the scientific establishment, and the public, to increased research expenditures remains high: this is where the lobbying efforts of the gay and lesbian community and its allies have been and are likely to remain most effective.

Summary of funding: In fiscal year 1981 \$0.2 million was spent on AIDS research; in fiscal year 1982 \$5.5 million; in fiscal 1983 \$29.0 million. In the current fiscal year, FY 84, \$47.4 million is budgeted thus far; this represents more than a 300% increase over the mere \$14.8 million that was projected by the Administration in early 1983 -- this increase came in part as a result of the lobbying efforts of the gay/lesbian community. At this point a budget for FY 85 -- which begins 10/1/84 -- has not been enacted; however, the Administration indicated earlier this year that they expected to request \$53.9 million in research monies for that fiscal year. The figures for FY 84 and FY 85, which could still be revised upwards in coming months in response to lobbying efforts, are as follows:

<u>Agency</u>	<u>FY 84</u>	<u>FY 85</u>	<u>General Purpose of This Funding</u>
Centers for Disease Control	\$12,000,000	\$12,000,000	Surveillance and Epidemiology
National Institutes of Health	34,159,000	40,316,000	Laboratory and Clinical Research
Food and Drug Administration	400,000	475,000	Blood Products Safety
Alcohol, Drug Abuse, Mental Health Admin.	866,000	1,100,000	Mental Health and IV Drug Research
Total	\$47,425,000	\$53,891,000	

Opportunities for Funding Increases in Spring/Summer 1984: As we have noted in our advisories and press releases in the past 6 months, a supplemental appropriations bill is a likely vehicle for additional AIDS research funding in fiscal 1984. NGTF and other organizations have been lobbying for a supplemental for the past several months. Very recently the House Appropriations Subcommittee for Health and Human Services, in the course of its "mark-up" of the Public Health Service supplemental budget, gave consideration to additional funding for AIDS research; the level of funding that they decided upon has not yet been made public (i.e., it is "embargoed"). At the moment, the Administration's formal request for a

supplemental AIDS appropriation has not been received by Congress. However, internal documents from the Public Health Service would indicate that, largely on account of the new research that must undertaken in the wake of the HTLV-3 discovery, the Administration will request at least \$15 million in additional funding for FY 84. We are also currently awaiting the Administration's revised request for FY 85, which, again in light of the HTLV-3 announcement, should be substantially higher than the current figure of \$53.9 million. When the revised figure is made public, it will be subject to the scrutiny of Congress and the various organizations, including NGTF, that are involved in monitoring the federal response to AIDS.

Funding for Community-Based Education: Our current objective is to convince Congress to direct that \$1.0 million of the FY 85 education monies of the Public Health Service be made available to local AIDS service organizations in the form of grants.

Timetable for Lobbying: It is likely that a supplemental appropriations bill will be enacted by Congress prior to the summer recess. Similarly, we can expect to hear of the Administration's revised request for FY 85 in the next 4 to 5 weeks. AIDS service organizations and other concerned individuals should lobby their congresspersons, particularly if they serve on the House Appropriations Committee, for passage of a substantial supplemental appropriations bill for fiscal 84. A final decision on the FY 85 budget may not come until September; it nonetheless important to lobby Congress now for substantially more research funding than the Administration's current request (\$53.9 million) and for at least \$1 million to go towards community-based education efforts. Though it won't hurt to send a letter or mailgram to the Whitehouse, lobbying of our congresspersons is likely to be a more effective approach.

Qualitative Considerations: What is still needed is an independent assessment of the Administration's overall plan for combatting the epidemic. Such an assessment could answer some serious questions about the scope and overall adequacy of the Public Health Service's response: are all avenues of treatment and theories of causation being adequately explored. Even though it seems likely, based on circumstantial evidence, that HTLV-3 (and/or LAV) plays a significant role in the development of AIDS, it is still entirely possible that other agents act as co-factors in the development of the syndrome in its most severe forms. At the moment, we have expectations that as a result of pressure from NGTF and our allies on Capitol Hill, this much-needed independent assessment may be underway by the early fall.

For further information about the federal response to AIDS and the role the gay/lesbian community can play in maximizing the level of that response, contact NGTF's Washington Representative, Jeff Levi, at 202-332-6483, or NGTF's AIDS Program Coordinator, John Boring, at 212-741-5800.

6/1/84

AIDS ADVISORY

NATIONAL GAY TASK FORCE
80 FIFTH AVENUE
NEW YORK, NEW YORK 10011
(212) 741-5800

APPLYING FOR SOCIAL SECURITY BENEFITS: THE BASIC FACTS
(Plus Some Notes on Medicaid and Medicare)

The Social Security Administration (SSA) announced on July 15, 1983, that it had made permanent its April 26 instruction that made it much easier for persons with AIDS to qualify for benefits under the two programs administered by the SSA, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). (See attachment for the text of the permanent manualized instruction). The April 26 instruction--which was teletyped to SSA district offices at that time--caused AIDS to be added to the list of recognized impairments.

The effect of the new policy is that persons with AIDS will be considered "disabled" if they are unable to "engage in any substantial gainful activity"--i.e., they are not working--and if they meet the SSA definition of AIDS. That definition requires an opportunistic infection to be present as well as the underlying clinical indications of the syndrome. (It is derived from the CDC definition.) Furthermore, to actually receive SSDI or SSI the applicant must also meet certain financial eligibility requirements (which are detailed below).

There are two stages in the application process: to obtain benefits the person with AIDS must first apply at a local district office (list for your geographic area is attached). Claims can also be initiated by phone using the SSA Teleservice: the claimant is sent the necessary forms for completion at home. Unless it is certain that the claimant will not qualify for one of these programs, the person with AIDS should file applications for both. The local district SSA office will determine whether the claimant qualifies for SSI, SSDI, or both. Please note that the forms should be signed and returned the day they are received even if the applicant is without all the required information at that time. Supplemental information can be filed to fully complete the application at a later date; by sending the forms a.s.a.p. the claimant establishes the earliest possible "date of application", which as noted later is of critical importance to early receipt of SSI.

When and if the claimant has met financial eligibility requirements for SSI and/or SSDI, the application is referred onto the nearest state-run disability determination office, where the claimant or his/her health care provider will be asked to provide medical verification indicating that they have the syndrome and that they suffer from an AIDS-related opportunistic infection--including but not limited to Kaposi's Sarcoma and Pneumocystis carinii pneumonia (see the manualized instruction for the list of recognized opportunistic infections).

Social Security Disability Insurance:

The person with AIDS will meet the financial eligibility requirements of SSDI if:

--the claimant has had a minimum amount of earnings (see below) for at least 20 of the past 40 quarters (i.e., quarter year periods).

or

--if the claimant is 31 or younger and has earned a minimum amount of earnings for at least half of the quarters since reaching age 21.

The earnings must be verifiable and have resulted in F.I.C.A. payroll deductions. Up until 1978 to qualify for a quarter of coverage you had to earn \$50 in that particular quarter; starting in that year you could earn a quarter of coverage for each \$250 in earnings, up to a maximum of four, that you earned anytime in that calendar year. Therefore if you earned \$1,000 entirely in the months of March and April, you will still have earned the maximum four quarters of coverage for 1978. The amount equal to a quarter of coverage has increased for each year as follows: 1979=\$260; 1980=\$290; 1981=\$310; 1982=\$370.

The purpose of SSDI is to provide replacement income for persons who are unable to work due to disability (and also for retired persons and the blind). The amount the person with AIDS is eligible to receive in SSDI grants depends on prior income and employment record. Payments range in amount from as little as a few dollars per month--for persons with a very limited work history at low pay--to in excess of \$500 per month for persons with a long and continuous work history at or above the highest F.I.C.A. levels of contribution (corresponding in 1983 to a salary of \$35,000 per year). Payment in the range of \$300 to \$400 are more typical for the person with AIDS in his thirties and with an average work history.

The claimant becomes eligible for SSDI five months after the onset of AIDS, or as the SSA frequently states it, at the beginning of the sixth month of disability. It is possible, if one's SSDI payments are low (less than \$347) to receive an SSI stipend in addition, (though one would have to meet the eligibility requirements for SSI that are described on the following pages). Also, if the claimant qualifies for SSI, s/he can receive that benefit until becoming eligible to receive SSDI benefits.

The date of onset for AIDS is often difficult to establish exactly; the manualized instruction specifies that "the onset . . . will be considered to be the date medical findings demonstrated the pneumonic or disseminated opportunistic infection or disease. However, the instruction also stipulates that "an earlier date of onset of disability may be established if this is dictated by documented medical findings in the case." The SSA notes further

documented medical findings in the case." The SSA notes further that "these findings must include medical reports showing treatment for a severe illness considered to represent a disabling impairment." This latter criterion has in some cases been interpreted so as to allow the date of onset to be considered the date for which there is medical evidence of AIDS-related symptoms, rather than the date on which a severe opportunistic infection was recognized -- which in some cases is many months later than the date of actual diagnosis.

Supplemental Security Income:

In contrast to Social Security Disability Insurance, Supplemental Security Income (SSI) is a needs-based program available to persons with AIDS with very little in the way of income and resources. A person with AIDS can qualify if s/he:

--has no more than \$1500 in resources

and

--has an income of less than \$314.00 per month

However, some of the claimants resources and income are exempt from consideration. Included in the definition of resources are valuables and all forms of monetary resources, whether they be cash, savings accounts, or stocks/bonds; certain possessions--a home, a car needed for employment, and materials needed for medical or the aid of the handicapped, and money committed to a burial fund--are not counted in the computation of resources. There is a formula that is used to compute income that counts towards the income limit: the first \$20 in income is disregarded; beyond that \$65 of earned income and \$1 out of every \$2 of additional earned income is disregarded.

Though it is true that a person with AIDS will not qualify as disabled if s/he is performing "substantial gainful activity," if either at the time of application or after the onset of benefits the claimant finds that s/he is capable of modest part time employment, the claimant will not necessarily be ruled ineligible on the basis of the "gainful activity" rule. Earnings in excess of \$300 per month are generally presumed to be "substantial," while earnings of less than \$190 usually will not disqualify a claimant on the basis of this rule; earnings between \$190 and \$300 may or may not be considered substantial. It should be kept in mind that it is easier to obtain benefits if the claimant is not working in any capacity whatsoever at the time of application. There is a provision of SSA regulations by which a person with AIDS already receiving benefits can recommence work on a limited trial basis of up to three months without losing their disabled status (this applies to SSDI as well).

The SSA provides a monthly stipend to those who qualify for SSI. The level of assistance that the claimant is eligible to receive will depend on what outside income is received according to the formula, and whether you are sharing living expenses with another person. The level of federal assistance is equal to \$314.00 in the case where the claimant has no income by virtue of this formula; otherwise the size of the payment will be \$314 minus all countable income. (Some states supplement the SSI stipends; New Jersey, for example, adds \$27; New York adds \$61; in these states the income limit for SSI qualification is correspondingly higher.)

However, in the event that the SSA determines from the application that a claimant is being supported by another person, SSI payments will be only two thirds as large. Thus, if you are living in the household of another person and you are not contributing significantly towards food and shelter, payments will be only \$209.34. (This level is supplemented by some states; e.g., New York State adds \$8.24.) If on the other hand you are living with a roommate or lover and are sharing expenses with that person in a roughly equal fashion, you will still be eligible for the full federal complement of SSI benefits, (though in those states that supplement the federal benefits the amount of the state contribution may be less than for someone who is living alone).

It is important to note that all monetary gifts received from friends, lovers, or other relatives, or any money that is provided by an AIDS Service Organization as an outright gift, must be counted as unearned income. Loans, on the other hand, do not count as income; as a result some individuals and AIDS Service Organizations may choose to provide financial assistance in the form of loans.

Eligibility for SSI payments is retroactive to the date of application. Therefore, it is important that persons with AIDS apply for SSI as soon as they are financially eligible. Even if the application takes three months or more to fully process, "claimants who qualify will receive grants retroactive to the date of application." To establish the earliest possible "date of application" for the purposes of SSI, it is advisable to return the SSA forms the day they are received regardless of whether all the information can be provided at that time; completion can take place after the form has been received and after the date of application has been established.

In the event that the claimant's level of resources is slightly above the \$1,500 maximum at the time of application, SSA will allow the claimant several weeks to spend down to below maximum. Under these circumstances, s/he need not repeat the application process. However, the SSA is required by statute to verify that the money was spent on medical or living expenses. If a large sum was merely withdrawn as cash, or given to a friend in order to qualify by virtue of the resource limit, SSA may deny the claimant SSI benefits. (SSA will require documentation of bank account balances, etc.)

One effect of the new SSA policy of regarding AIDS is that persons with AIDS can now obtain SSA benefits on the basis of "Presumptive Disability" prior to the official determination of disability that can take place only after processing all the requisite paperwork. The claimant can receive SSI payments for up to 90 days on the basis of a ruling of Presumptive Disability. (It is not clear that this option is being utilized on a regular basis anywhere except in New York City).

During the period when a person with AIDS is waiting for approval of an SSI claim (and when the benefits have not been obtained on the basis of a Presumptive Disability) it is possible in some states to obtain public assistance from the state welfare department. In New York, for example, under a provision called

letter of referral to the Division of Social Services; that letter--which is based on a preliminary judgement that the claimant will ultimately qualify for SSI--should enable persons with AIDS to obtain New York State public assistance almost immediately. Under this arrangement, the public assistance payments constitute a loan from the state to SSA; part of the first retroactive SSI check is automatically routed to the state for reimbursement purposes; the remainder and all succeeding SSA payments are sent directly to the person with AIDS.

Some persons with AIDS have had their claims for SSI/SSDI "allowed" by the state offices of disability determination by virtue of the "equal to" provision of the SSA policy. This provision was the principal means by which some persons with AIDS attained "disabled" status prior to the April 26 instruction by virtue of a medical "rationale" that a person with AIDS was suffering from an opportunistic infection that was medically equivalent to a listed impairment. The "equal to" provision might still assist some persons with AIDS who do not have one of the opportunistic infections listed in the instruction to attain "disabled" status by virtue of having an infection "equal to" another opportunistic infection or another disorder recognized by SSA.

Appealing an Unfavorable Decision:

Since the issuance of the new policy in April, persons with AIDS who have an opportunistic infection seem rarely to have been rejected on medical grounds. But there is an appeal process for those who believe they have been wrongfully denied benefits.

Step 1: The claimant is allowed 60 days to appeal to SSA for a reconsideration (the first step in the appeals process). New or supplementary medical evidence can be presented at this time; wrongful denial of benefits has been rectified at this level for at least several persons with AIDS.

Step 2: If the claimant does not obtain satisfaction at this level, a hearing before an administrative law judge can be obtained, but that request must be filed within 60 days of an unfavorable decision at the level of reconsideration. The administrative law judges are allowed greater latitude in interpreting SSA regulations than SSA personnel at earlier stages in the claim review process; prior to the issuance of the new policy some persons with AIDS obtained benefits by virtue of a favorable interpretation of the SSA definition of qualifying disability.

Step 3: If the ruling at the hearing is unfavorable, the person with AIDS can file an appeal with the Social Security Appeals Council in Washington, DC within 60 days of the ruling by the administrative law judge.

Step 4: Finally, the claimant can make an appeal of last resort to the U. S. District Court; again, this appeal must be filed within 60 days of the last unfavorable ruling.

The person with AIDS who decides to pursue a rejected claim through the appeals process may choose any person of his/her choice as a representative/advocate, including but not limited to: a private attorney, an attorney or welfare advocate available through an AIDS service organization, or a lawyer available pro bono or at little cost through a gay lawyer's group.

See the attached list provided by Lambda Legal Defense and Education Fund for referrals in nine major cities. Outside these areas call your local hotline (or the NGTF Crisisline -- 800-221-7044/in New York State: 212-807-6016 -- if you don't have one in your area), or consult the The National Lesbian and Gay Attorneys' Referral Directory published by Gay and Lesbian Advocates and Defenders.

Federally Funded Medical Assistance:

Those persons with AIDS who qualify for SSI are generally also eligible for Medicaid. In many states, SSI recipients receive a Medicaid card whether or not they file a separate application: the SSI list of qualifying applicants is broken down by state by the SSA in Baltimore; the state list is sent to the state capitol where the state welfare agencies break down the list by county or district; the welfare office then mails out the card to the SSI recipient. However, this process typically takes 4 to 6 weeks after the SSI application is approved. Persons with AIDS can obtain Medicaid more quickly by applying directly to their respective state medicaid offices and by showing proof that they have qualified for SSI. There is a 90 day statutory limit on the time allowed for processing a Medicaid application. (Nonetheless, delays longer than three months have been reported.)

Medicaid, like SSI, is a needs-based program. It is designed to pay certain medical expenses of persons who have few resources or income. The program is administered by the states, though the Health Care Financing Administration (HCFA), a division of the Department of Health and Human Services, oversees its implementation. The states are allowed considerable leeway in establishing eligibility requirements and determining what kinds of medical expenses qualify for Medicaid reimbursements. The federal government pays 50% of the costs of Medicaid, the states 25%, and local governments the remaining 25%.

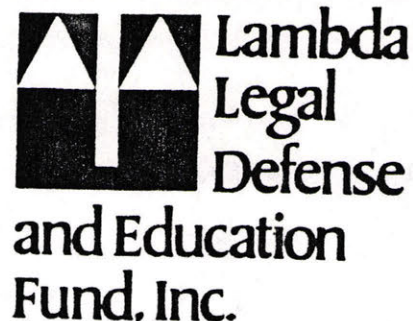
Implementation varies from state to state as far eligibility requirements are concerned. In New York, for example, you can qualify for Medicaid if you have less than \$2,600 in resources and \$350/month in income. Some experimental treatments and outpatient services--both of great significance to persons with AIDS--are typically not covered by the state-run Medicaid programs. Fortunately, some states, such as Florida and New York, have Medicaid spend-down programs which allow applicants to

deduct medical expenses from their income to "spend-down" to maximum allowable income levels. Given the inevitably high costs of treatment encountered by persons with AIDS, spend-down programs are very advantageous for persons with AIDS.

Just as Medicaid is similar to SSI in being a need-based program, Medicare is similar to SSDI in that it is available to the retired and the disabled regardless of the level of their personal resources or income. However, though disabled persons, including persons with AIDS, can qualify for Medicare, they are eligible only after a two year waiting period commencing from the date of onset. This has thus far rendered Medicaid useless for the vast majority of persons with AIDS. As treatment for AIDS improves, and the short term mortality rates for AIDS decline, Medicare will become of greater importance.

prepared 12/83

The NGTF AIDS Program wishes to acknowledge the assistance of Jeffrey Woodcox of the Social Security Administration, Jay Lipner, Special Counsel to the Gay Men's Health Crisis, Mindy Domb of Congressman Ted Weiss's office, and Tim Sweeney of Lambda Legal Defense and Education Fund in the preparation of this Advisory.



MEMORANDUM

To: National Gay Task Force
From: Tim Sweeney
Subject: Legal Services for People with AIDS
Date: October 18, 1983

Boston

Gay & Lesbian Advocates & Defenders (GLADI)
Two Park Square, Suite 300
Boston, MA 02116
(617) 426-1350

Chicago

Gay Horizons Legal Services Program
Box 1319
Chicago, IL 60657
(312) 929-HELP

Houston/Dallas

Texas Human Rights Foundation
1519 Maryland
Houston, TX 77006
(713) 526-9139

Los Angeles

Lawyers for Human Rights
P.O. Box 480318
Los Angeles, CA 90048

Miami - No organized legal services.

New York City

Pro Bono Panel of the New York Law Group
Contact: Steve Gittlesen
(212) 532-0350

Philadelphia

Philadelphia Lesbian/Gay Switchboard
3601 Locust Walk
Phila., PA 19104
(215) 386-1610

San Francisco

Bay Area Lawyers for Individual Freedom (BALIF)
AIDS Lawyer Referral Panel
Contact: Steve Richter
(415) 982-9211

(cont.)

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Legal Services/AIDS

Washington DC/Maryland/Virginia
Lawyer Referral Service of the Gay & Lesbian Switchboard
(202) 328-1213

There are the following national gay/lesbian legal organizations as well:

Gay & Lesbian Advocates & Defenders (GLAD) (See above listing)

National Gay Rights Advocates
540 Castro Street
San Francisco CA 94114
(415) 863-3624

Lambda Legal Defense & Education Fund
132 West 43rd Street
NY NY 10036
(212) 944-9488

Lesbian Rights Project
1370 Mission Street
San Francisco CA 94103
(415) 621-0675

Texas Human Rights Foundation (See above listing)



National Gay Task Force

80 Fifth Avenue • New York, New York 10011 • (212) 741-5800
Washington Office: 2335 18th St., N.W. • Washington, D.C. 20009 • (202) 332-6483

TESTIMONY ON THE FISCAL 1985 BUDGET FOR THE PUBLIC HEALTH SERVICE

Virginia M. Apuzzo
Executive Director

April 26, 1984
House Appropriations Committee
Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Washington, D.C.

Mr. Chairman, my name is Virginia Apuzzo. I am executive director of the National Gay Task Force. With me today is Tony Ferrara, a person with AIDS who will give the kind of human perspective to the AIDS crisis that can only come from someone who has fought long and valiantly against this mysterious disease.

Mr. Chairman, I come before you today both hopeful and cautious about recent developments relating to AIDS. We hope that the research findings announced on Monday by Secretary Heckler will indeed lead to confirmation that a cause for AIDS has been found. But even if this discovery is verified—and that will take time—it is only the first step down a long road before the AIDS crisis is behind us. Until we are sure that an accurate test has been developed along with a vaccine and effective treatment, our vigilance and our efforts cannot cease.

We cannot forget that AIDS remains a major health crisis. The number of cases continues to rise at an alarming rate. As of April 16th, according to the Centers for Disease Control, there were 4087 cases, with a mortality rate of 43 percent. The number of cases has tripled over the last year. This kind of growth rate makes essential a renewed and increased commitment on the part of the federal government to finding a treatment and cure for AIDS.

We would not have arrived at this point, however, without the dedicated work of many scientists within the Public Health Service and around the world. The fact that the resources were available to do this work is a result, in large measure, of the support for AIDS-related activities that has been found on this Committee, and the pressure that you, Mr. Chairman, have maintained on the Department of Health and Human Services to get the job done. For that, Mr.

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Chairman, the entire gay/lesbian community owes you a considerable debt of gratitude.

Until now, funding has increased at a rate that has kept pace with the growth of the epidemic. In such instances, a special case can and must be made for major funding increases, even during times of fiscal constraint. The Administration's request of \$53.9 million for AIDS-related activities for fiscal year 1985 is a far cry from the \$5.5 million spent in fiscal year 1982. But even more dramatic was the Administration's more than doubling of its own 1984 budget request within the space of just a few months—from \$17.6 million to \$39.8 million, with Congress wisely adding nearly \$8 million more (for a total of \$47.4 million).

We want to make absolutely clear that we do not seek increases in spending on AIDS at the expense of other important health programs. Thus, while we are encouraged that the Administration's current budget has requested a \$6.5 million increase for AIDS, we are distressed that it has proposed a \$4 million cut in the CDC's work on infectious diseases and the elimination of a \$5 million categorical grant for tuberculosis control. It is unconscionable that, since beginning its work on AIDS, CDC has discontinued projects on the herpes virus, papillomavirus, and cytomegalovirus. The first two are leading candidates in the search for the cause of uterine cancer—which causes 7,000 deaths every year. Health care is a vital national interest—one that our economy and budget, no matter how serious our fiscal problems, must always afford to address.

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I come before you today to discuss the work that still needs to be done,

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even after Monday's announcement. All work underway must be continued to make sure we solve the problem in its entirety. Remaining leads that research has developed should be pursued—because of what they may tell us about AIDS, and just as importantly, because of the implications this research may have for basic immunology and cancer research as well. The overall importance to medical research of this work should not be underestimated.

From Monday's announcement come several new research areas of concern:

- o Verification of the HTLV-3 virus as the cause of AIDS requires considerable testing—most probably on an animal model, which is a costly and time consuming activity. Once verified, the question of cofactors must be studied: what other factors play a role in susceptibility or predisposition to the HTLV-3 virus?

- o It must be determined if the HTLV-3 virus is indeed the same as the LAV virus being investigated in France.

- o The possibility of a test for HTLV-3 raises interesting questions about distribution and cost—is the government willing to bear the cost of the test to assure its availability for all who need it?

- o And with the isolation of a virus, comes the hopeful prospect of developing a vaccine. That, too, is a lengthy and costly process. The hepatitis B vaccine took some ten years to develop at considerable cost.

Given these new funding issues that arise from the identification of HTLV-3, we urge this committee, Mr. Chairman, before it votes on a 1985 budget, to ask the Administration to identify how much additional funding verification, testing, and development of a vaccine will require—and whether different levels of funding might bring speedier results.

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Even with this discovery, many more research questions remain unresolved. Basic research about transmission and treatment must continue with renewed vigor. And it is in these still unresolved areas that we have grave concerns about spending levels that have been requested by the Administration in fiscal year 1985 for AIDS-related activities. We believe far more is needed than the level funding requested for CDC and the marginal increases requested for NIH and other PHS agencies. We also believe that new initiatives are necessary, notably the funding of public education and prevention activities by community-based organizations.

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It is not my intention to review every aspect of the AIDS budget. But I think a quick review of several of the funding proposals will make clear the need for increased spending levels.

o The CDC's AIDS activities are level funded at \$12 million for fiscal year 1983. This does not even allow for increases caused by inflation. More money and more personnel are needed just to do the basic surveillance and epidemiology associated with the increasing numbers of cases. Level funding would not even permit CDC to maintain its current scope of activities nationwide. The isolation of a virus may actually increase some of CDC's work. Development of a blood test for HTLV-3, which now seems possible, will allow for more and better surveillance and epidemiology: we will be able to identify and follow more AIDS cases earlier and more precisely. And we still need epidemiological studies to help determine what factors place individuals at greater risk to AIDS.

By the CDC's own admission, the \$12 million it received in fiscal 1984

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forced it to forego projects worthy of funding. Last November, for instance, CDC convened a conference of researchers to help it choose among a series of proposals—all judged worthwhile—because there were insufficient resources to carry them all out.

o A similar situation exists at the National Institutes of Health. For example, the National Institute of Allergy and Infectious Diseases, where 40 percent of NIH's AIDS work is being done, has the lowest payline [reflecting the number of approved projects that are actually funded] in all of NIH—30 points below the payline for the National Cancer Institute. I know this has been a source of considerable concern to you, Mr. Chairman, over the last several years. The only explanation for this discrepancy is that NIAID has inadequate resources. And yet its AIDS budget for fiscal year 1985 goes up by only \$1.3 million (compared to \$2.6 million for NCI).

o Additional funding is also needed to accelerate research specifically directed toward more effective treatment for this devastating illness. The discovery of the cause of AIDS may make this job a little easier, especially if a blood test can identify cases early on. But it does not immediately affect the over 2300 persons who now have CDC-defined AIDS, or the thousands who may develop AIDS before a vaccine is developed, or the thousands of others with pre-AIDS conditions. While we seek a cure, we must also be seeking effective treatment of the disorder. The two are not identical: just as we do not have a cure for diabetes, but do have an effective treatment, a similar situation may develop for AIDS.

o We are just beginning to see research into the mental health or psychosocial aspects of AIDS: what role does stress play in the breakdown of

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the immunological system? Is stress a possible cofactor? Indeed, the development of a test for HTLV-3 may increase the need for such studies, given the additional stress for those who respond positively to a test that does not definitively diagnose AIDS. Addressing some of these questions in the context of AIDS will tie in well with a good deal of research now under way relating psychology to physical illness.

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There is another area that we feel is critical for the government to enter, if we are to have any success in reducing the spread of AIDS. That is community-based public education.

Even before the latest developments covering the possible cause of AIDS, gay community groups across the country have made concerted efforts to pass on to individuals what is known that might reduce their risk of contracting AIDS. It is a difficult task, but until a vaccine for AIDS is developed, nothing could be more important.

This type of health education is very different from that which seeks to reassure the general public not to panic about AIDS. That job is being done rather effectively by the Public Health Service and local health agencies. But reaching the groups at risk is something most effectively accomplished by community-based groups themselves. They have greater credibility than the government in discussing such a sensitive subject.

At present, direct assistance to community groups for this kind of effort is not seen as part of the federal mandate for health education. We therefore hope this Committee will direct the PHS to set aside specific funds that can be channelled to community-based groups for public education of groups at risk.

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With a little help from the government, our hard-pressed efforts could become much more effective.

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One of our continuing concerns about the federal response to AIDS has been the lack of a master plan of attack—one that systematically outlines the work already underway, the approaches and underlying assumptions of the effort, the contingencies that are anticipated, and how research by government agencies and outside scientists is coordinated. As promising as Monday's announcement seems, some press accounts have revealed the degree to which there was not sufficient cooperation among government scientists and with scientists outside this country.

In our testimony before this committee last year, we advocated the creation of an independent panel to assess the federal government's work on AIDS. Now that a virus may have been isolated, such an independent assessment is even more important for determining how best to verify this discovery and create a model for developing a vaccine and effective treatment for AIDS. We therefore urge this Committee to direct that an independent, objective assessment be conducted to resolve these outstanding questions.

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A major lesson we have learned about our public health system through the AIDS crisis is that there is no mechanism for an immediate infusion of research money once a new disease or medical emergency has been identified. The Public Health Emergency Fund would do just that—setting aside money that can be used by the Secretary of Health and Human Services to meet a crisis immediately. We urge this Committee to appropriate funds in this budget cycle so that there

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will not have to be any delays in dealing with a future crisis.

There is one more aspect to the AIDS tragedy: the extraordinary health care costs associated with treating the syndrome. The financial burden AIDS has placed on the individual person with AIDS as well as the public hospitals to which many have turned for care is astounding. New York City has estimated that it spends \$73 million a year in hospital costs alone; other cities have also had to assume extraordinary costs. I mention this to remind you that the money spent on AIDS research and public education will be saved many times over if we can prevent just a few people from getting this deadly syndrome.

In summary, Mr. Chairman, I call on you to continue to exercise your wise and caring leadership in this vital area—by appropriating additional monies for AIDS-related activities, directing that some of those monies be channelled to public education for groups considered at risk, and funding an independent assessment of the government's efforts and plans for AIDS research. The very lives of thousands of people, including many in my community, depend on the success of these efforts.

I would like to introduce to you now Tony Ferrara, a person with AIDS from Washington, D.C. who has been a pioneer in fighting the disease and will relate to you some of the personal impact of AIDS and also how well our community has responded to this crisis.

Thank you very much.