

## The 76th Annual Meeting Special Lecture

# A DECADE OF SUCCESSFUL TUBERCULOSIS CONTROL IN NEW YORK CITY

–The Role of DOT vs DOTS–

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**Key words:** New York City, Tuberculosis control, DOTS, DOT

### Introduction

I would like to review how New York City (NYC) has faced the problem of tuberculosis (TB), and successfully reduced it currently through the DOTS strategy.

My take-home message is that if a place as big and diverse and complicated and crazy as NYC could accomplish what we accomplished, then Japan can too. You may implement activities in a different way, but the principles are the same.

### Brief History and Background of TB Control in New York City (NYC)

Many of the basic precepts of modern tuberculosis (TB) control, including laboratory diagnosis, isolation of infectious cases, reporting of cases to public health authorities, outreach to patients in their homes and public education about tuberculosis, were developed and refined in the late 1800s by Dr. Hermann Biggs of the NYC Department of Health, which is today still responsible for tuberculosis control activities in NYC. He remarked that compared with TB, “all other communicable and reventive diseases sink into relative insignificance”. He used the pioneering work of Dr. Robert Koch, who showed that TB was a communicable disease caused by a bacterium and proposed a systematic approach to tuberculosis control. These included: 1) mandatory notification of all TB cases; 2) the use of the acid fast bacillus smear, a highly effective diagnostic tool, to diagnose infectious cases, and provided for free; 3) patient follow-up by nurses to provide the best treatment available at the time—bed rest, fresh air and good nutrition to reduce the spread of transmission, and to provide education about transmission; 4) education of physicians, patients and the public (he had materials translated into German, Hebrew, Italian and other languages), and 5) he strengthened political will to gain financial and administrative

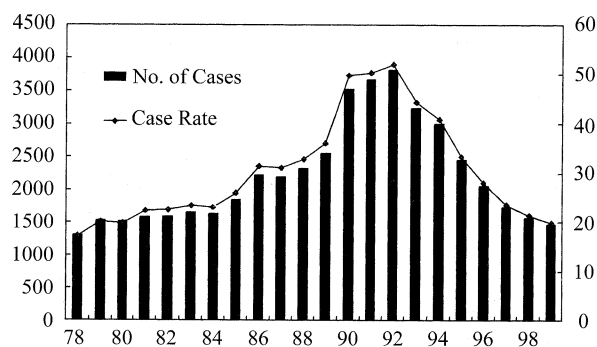
support for his programs.

He did his work against great resistance by the medical establishment, who opposed mandatory notification as a violation of the doctor-patient relationship. His educational messages had the unintended consequence of stigmatizing the communities that were most affected. On balance, however, his efforts led to the creation of an administrative framework for TB control still applicable today.

Sadly, NYC did not heed its own lessons. By the late 1970s and throughout the 1980s, the number of tuberculosis cases started to rise, and almost tripled by early 1990s (Fig. 1). There were 4 causes for this resurgence of TB; 1) dismantling of the TB control infrastructure, 2) immunosuppression from HIV, 3) lack of infection control in hospitals, and 4) immigration from high TB prevalence countries.

### Dismantling of the TB control infrastructure

NYC's local government and the US federal government withdrew funding for TB control in the late 1970s and throughout the 1980s. Between 1970–72, the US federal gov-



**Fig. 1** Tuberculosis Cases and Rates, New York City (1978–1999)

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ernment phased out direct monetary support to cities, and then between 1974–78, NYC underwent a fiscal crisis.

In 1979, the state of NY terminated its funding. In 1979, some renewed funding came from the federal government, but a year later, in 1980, this was reduced significantly.

In addition, Brudney and Dobkin reported on 224 patients at a NYC inner city hospital serving the poor. Of 224 consecutive patients suspected of TB that were admitted to the hospital, 53% abused alcohol, 64% abused drugs, 68% were homeless or unstably housed, and 50% were HIV positive. Of the 178 discharged from the hospital on treatment, 89% were lost.

Staff in the program confirmed that they spent their time finding patients, then would lose them, but no resources were available to track them down again.

*Immunosuppression from HIV*

There was a large population of HIV-infected individuals in NYC, who once infected *M. tuberculosis*, developed TB disease rapidly. About one third of the patients with TB were infected with HIV (Fig. 2). However, because so many of the TB patients did not have an HIV test done, this is a minimal

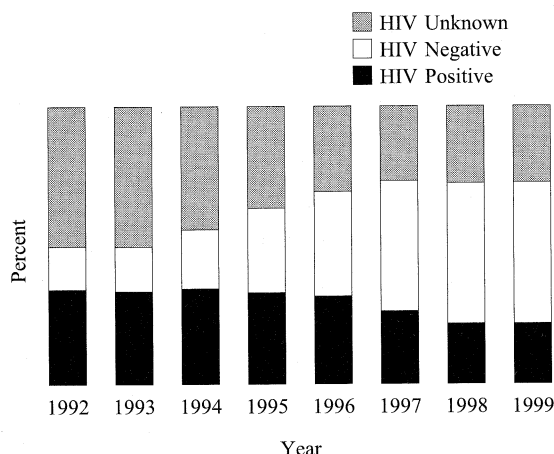


Fig. 2 TB/HIV Co-infected Cases (1992–1999)

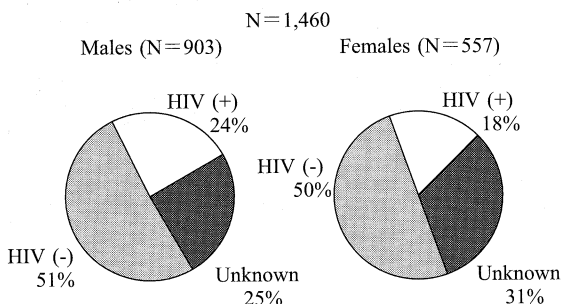


Fig. 3 HIV Infection and Tuberculosis, New York City (1999)

estimate, and we estimate there was approximately 40% co-infection. In 1999, however, this had declined to 22%.

Fig. 3 shows the data in 1999 stratified by sex. Males are more likely to be documented to be HIV infected. While the HIV status is not known for about 25%, this has declined from the early 1990s when over 50% did not have their status recorded.

*Lack of Infection Control*

The lack of infection control in hospitals caused them to become amplification centers for TB. During the NYC's nosocomial outbreaks, the average length of time between diagnosis and death was 4–16 weeks. The outbreaks involved 11 hospitals, where 357 patients met the case definition of resistance to isoniazid, rifampin, ethambutol and streptomycin, and 25% of the MDR-TB cases in the United States occurred in NYC between 1990 and 1993. 267 had identical or nearly identical strains (strain W – resistant to isoniazid, rifampin, ethambutol, pyrazinamide, streptomycin, kanamycin, ethionamide); 86% were HIV-infected; 70% were epidemiologically linked, and 96% were nosocomially transmitted. The outbreaks also infiltrated into the New York State prison system. Since it was the policy of the state prison system to move prisoners around from prison to prison, eventually the strains of TB were seen in 23 of the 56 prisons. Strain W also spread from NYC to more than 40 of the 50 states.

The development and continued presence of MDR-TB in NYC reflected the historical neglect of the TB program. The scenario was that patients didn't take the medications properly; the strains developed drug resistance; they continued to be infectious and spread MDR-TB to others, including the health care workers within the hospitals, and also to those in the community. Doctors didn't know how to treat the drug-resistant strains, and created more drug resistance. The patients continued to be infectious and the vicious cycle continued.

It is hard to convey the sense of panic, hysteria and crisis that was in NYC at the time. People were dying, including some health care workers who were caring for them. The hospitals were not environmentally safe. The newspapers were full of stories about TB, tourism was affected, the health department was besieged with calls from professionals and the public. When I was preparing to interview for the position of MDR-TB coordinator in NYC, I sought the advice of colleagues and professors. All discouraged me from taking the position, saying that the bureaucracy of NYC was too difficult to accomplish anything.

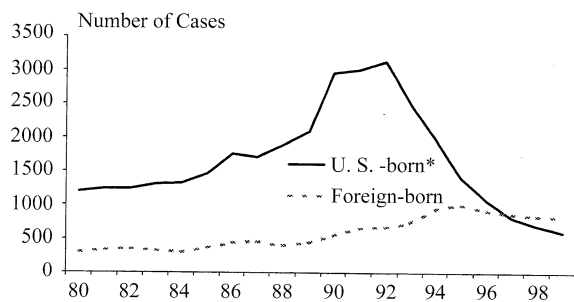
*Immigration from high TB-burden countries*

Between 1992 and 1999, the proportion of TB cases among the foreign born increased 228%, from 18% in 1992 to 58% in 1999 (Fig. 4). By 1997, the number of TB cases reported among the foreign born exceeded that of those born in the US. Fig. 5 shows the cumulative number of foreign-born TB

cases. The countries of origin by level of morbidity were Puerto Rico, China, Dominican Republic, Haiti, Ecuador, Mexico and India.

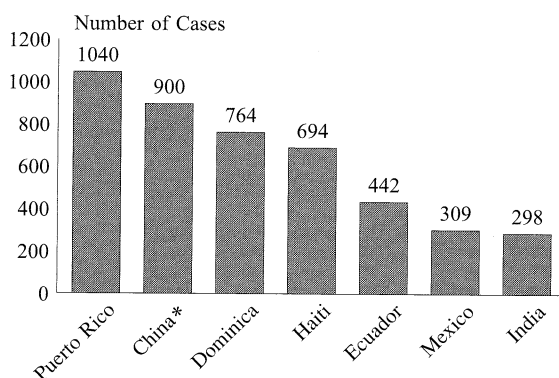
*Social Characteristics of TB Cases*

The TB patients in New York City face many challenges in addition to their disease (Table 1). A significant proportion



**Fig. 4** US and Foreign-Born TB Cases, New York City (1980-1999)

\*Puerto Rico and U.S. Virgin Islands are included as U.S.-born



**Fig. 5** Cumulative Tuberculosis Cases from Selected Countries, New York City (1992-1999)

\*Includes Peoples Republic of China, Taiwan, and Hong Kong

use excessive amounts of alcohol and/or use drugs. Although the number of homeless at the time of diagnosis or during treatment is relatively low, a significant number have had a history of homelessness before diagnosis. There is some risk to health care or correctional workers.

**Epidemiologic Trends of TB in NYC**

Fig. 1 shows the overall trends of TB cases and rates in NYC from 1978 to 1999. TB increased until 1992 but since then has decreased dramatically; the rate went from 50.2 to 19.9/100,000; cases from 3,811 to 1,460, a decline of over 60%. Data for 2000 shows a further decline, and the lowest case rate ever recorded in NYC.

*Age Distribution of TB Cases by Year*

The pattern of age distribution of TB cases has changed over the years (Fig. 6). Between 1992 and 1999, 69% fewer cases have been reported in the 25-44 year age group. The pattern seen in NYC resembles that in the developing world. From 1992 through 1999, there has been a 69% decline in the 25-44 year age group, i.e. the young and middle-aged adults, as the rate of HIV has declined.

*Drug Resistance by Previous treatment*

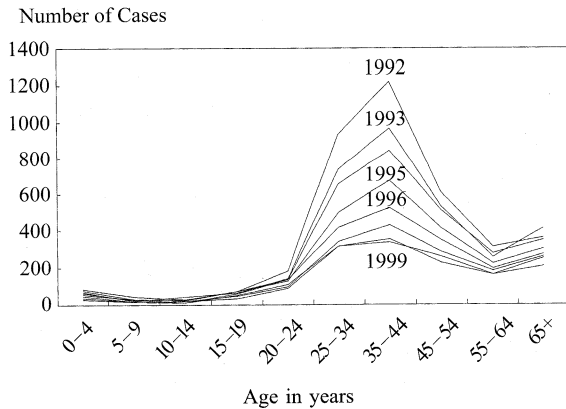
A survey performed in April 1991 showed that drug resistance was high in NYC (Fig. 7). 30% of those who had previously received some treatment for TB, but had not necessarily completed treatment, had TB strains resistant to isoniazid and rifampin, the two most powerful medicines available to treat TB. Among those who had never been treated, 6% were infected with these MDR (Multi drug resistant)-TB strains. In contrast, at the same time in the United States, just 3% of all cases in a national survey had MDR-TB, for which NYC contributed two-third of the cases.

*MDR-TB (1991-1999)*

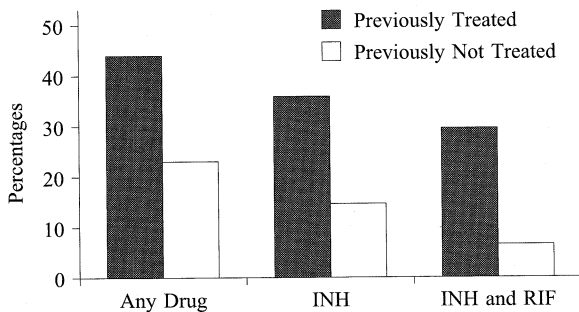
The number of cases of MDR-TB declined dramatically from the peak in 1992 (Fig. 8). This was attributable to several factors: 1) the rapid deaths of the outbreak cases, de-

**Table 1** Social Characteristics of TB Cases, New York City, 1999

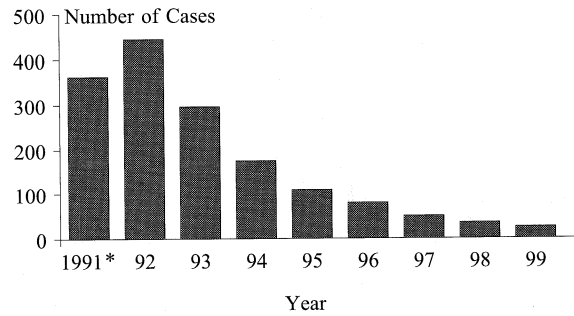
Characteristic	# Cases	% Cases
Injection drug use (within 12 months)	47	3
Non-injection drug use (within 12 months)	124	9
Alcohol abuse (within 12 months)	186	13
Homeless (time of dx or anytime during tx)	77	5
Correctional facility (time of dx)	45	3
Long-term care facility (time of dx)	27	2
Health care or correctional facility worker (within 24 months)	50	4



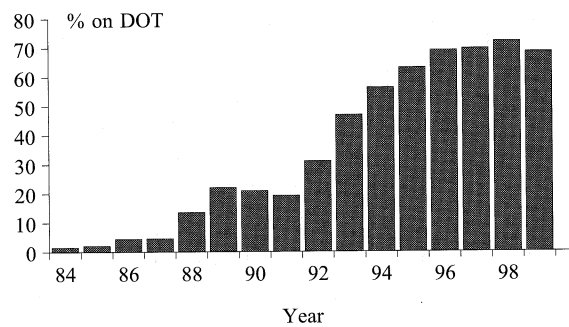
**Fig. 6** Tuberculosis Cases by Age, New York City (1992-1999)



**Fig. 7** Drug Resistance by Previous Treatment, New York City (1991)



**Fig. 8** Multi-Drug Resistant Tuberculosis, New York City (1991-1999)  
\*1991 data are incomplete



**Fig. 9** Percent of Eligible Tuberculosis Patients\* on Directly Observed Therapy, New York City (1984-1999\*\*)   
\*Those diagnosed and received some treatment on an outpatient basis  
\*\*Ever on DOT as of March of the year

creasing the time available to spread TB, 2) the improvement in the TB control program, specifically the use of DOT, 3) the intensive case management of those with MDR-TB, and the availability of drugs to treat them.

From a peak of approximately 450 cases in 1992, approximately 30 cases were reported by 1999. New cases of MDR-TB have practically been eliminated. However, we are left with a group of chronic cases, almost all HIV negative, who have been unresponsive to all treatment. Three have court orders for home isolation.

**Directly Observed Therapy (DOT) in NYC**

One of the key elements in the battle against TB in NYC was the implementation of directly observed therapy (Fig. 9). In 1992, when I arrived in NYC, DOT was reserved only for the so-called "difficult" patients. Despite this policy, TB, and especially MDR-TB had spiraled out of control. Numerous studies have shown that it is not possible to predict with any certainty who is going to adhere to taking medications. It has been shown NOT to be correlated with: level of education, socioeconomic status, type of profession, gender, marital status, age, etc. We made the decision, despite great skepticism that it could be done and resistance to the idea that it

SHOULD be done, that DOT was a service that would be offered to everyone as the best way to provide treatment. We started in July of 1992, and set a goal of 500 patients on DOT by December. We initiated extensive training of all staff in the program, as embarked on a series of lectures to the medical providers in the community, concentrating on university professors and medical centers, who would be seen as innovators. With their support, they in turn worked within their own institutions to spread the word about DOT. When we reached 550 people on DOT by December 31 of that year, it was a moment of great pride and a realization that we could change attitudes and practice. When the number of cases dropped by 14% the following year, we were ecstatic.

Approximately 69% of all patients in NYC have their treatment under DOT. Given the nature of the medical system in the United States, DOT in most instances is voluntary, and we must rely on convincing physicians and patients that this is the most effective method of treatment. Those with MDR-TB are our highest priority, given that this is their last chance for cure. Persons with pulmonary smear positive, that is infectious TB, are also given high priority. If a person has come to one of the clinics run by the Department of Health of NYC,

**Table 2** 5 Elements of a Good TB Control Program (DOTS Strategy)

1. Political will
2. Laboratory is able to diagnose cases promptly and accurately
3. Direct observation of treatment (DOT) to prevent drug resistance
4. Adequate supply of medications
5. Systematic review of results

over 80% have their treatment under DOT. Patients cared for by private doctors have the lowest rate.

#### Implementation of DOT in NYC

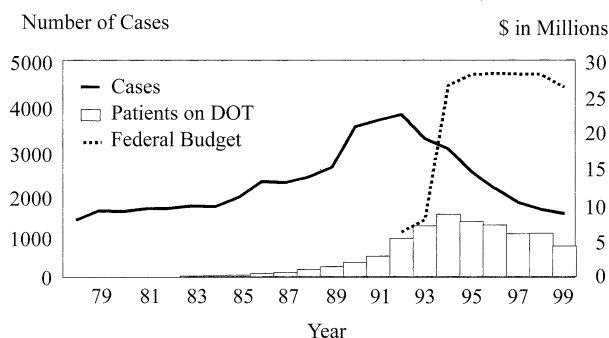
There have been a various practical points to note in implementing DOTS: 1) In the beginning, we had to overcome intense resistance of physicians and staff; 2) Patient could decide where/when DOT is given; 3) Patients are provided with enablers, longer clinic hours, transportation tokens, and biweekly treatment; 4) Patients are also provided with incentives such as cash equivalents and meals on site.

#### Summary

In summary, through our intensive efforts, TB declined significantly in NYC between 1992 and 1999. The new TB cases decreased by 62%. New cases of MDR-TB have been reduced by 93%. US-born cases, particularly among the young to middle aged adults (25–44 years), who were heavily impacted by HIV, have declined by 81%. The proportion of HIV-infected cases decreased from 34% to 22%. However, the proportion of foreign-born cases has more than doubled from 18% to 58%.

#### Good TB Control Program: DOTS in contrast to DOT

How did we accomplish the above results? Looking back, we did begin to reapply the principles laid out by Hermann Biggs that I presented earlier. To achieve these results, NYC's TB Control followed the precepts of the pioneering work of Dr. Karel Styblo of the International Union Against Tuberculosis and Lung Disease (IUATLD), who developed it while at the IUATLD. His work was adopted by the World Health Organization, and relabeled by them as the DOTS (Directly Observed Treatment, short-course) strategy. However, naming this strategy DOTS, because of the close link to the concept of DOT, has caused great confusion and misunderstanding. To define them, DOTS is the whole package of five activities that defines good TB control, while DOT is only ONE of the five elements, the actual watching of the patient taking medication of the DOTS strategy package (Table 2). In NYC, we followed these the 5 specific precepts of DOTS, although we did not label it as such at the time.

**Fig. 10** Tuberculosis Cases, New York City (1978–1999\*)

\*1999 data are preliminary

#### Success of TB Program in NYC

The success of TB program in NYC can be explained according to the DOTS components:

##### Political will:

The first is POLITICAL WILL. There was strong support from the Commissioner of Health of NYC, the highest-ranking health officer. We lobbied successfully for increased funding from local, state and federal levels (Fig. 10). We sought and received support from university professors as “change agents”.

##### Laboratory services:

We improved the turn around time for results of AFB smear, culture and susceptibility, which was taking sometimes up to 4–6 months. Susceptibility testing was mandated, and surveillance for contamination was implemented.

##### Medication supply:

Free medication is available to all. Private doctors can obtain free medications for patients only if the treatment is done on DOT. For some special cases such as those with MDR-TB, experimental drugs are available under the protocol guidelines.

##### Systematic review of TB program results:

A system of quarterly cohort reviews of all patients has been established:

- 1) Review meeting: Oral presentations of the activities are made in group settings by the staff to the program director. The meeting is attended by physicians, nurses, managers and supervisors, out reach workers, social workers who are concerned with the program. Everyone is accountable for the results. The outcomes are tied to national goals and objectives.
- 2) Review of results: Based on the presentations, the results, mainly of treatment cohort, are calculated and fed back immediately for each case. The results are documented as completed, died, moved or abandoned treatment. The development of new goals is set up by the end of meeting.
- 3) Outcome of contacts examination: The outcome of con-

**Table 3** Treatment Cohort Review Results

	1992	1998
Treatment completion	<50%	93.5%
Contact index	2.5	5.3
Contact Evaluation	38%	87.8%

tacts to cases is also reviewed, such as number of contacts/case (contact index), number evaluated for TB, number infected with TB, number offered treatment for latent TB infection, number of people who start treatment, number of people who complete treatment.

Some sample review results comparing 1992 to 1998 is shown in Table 3. The quality of the program has improved significantly.

#### *Does Japan have these elements?*

As I end this part of the presentation, I want you to ask yourselves: dose Japan have these elements? Are they as good as they can be?

#### *Lessons learned*

The lessons learned in NYC can be divided into three types as follows:

- 1) Regarding TB control infrastructure:
  - a. The health department can serve as coordinator for all TB control in the community.
  - b. Having a manual for policies and procedures sets the standard for the community.
  - c. The health department has some unique responsibilities, such as surveillance, contact investigation, detention or dealing with the most difficult cases.
- 2) Regarding Patient care:
  - a. TB patients should be the center of all efforts.
  - b. The program should be run on a customer service model: the patient as customer, the doctors as customers, and the public as customer.
  - c. Since so many of the patients with TB are poor and disenfranchised, we as health officials must serve as advocates.
  - d. Following the tenets of Hermann Biggs, education is

needed to address stigma at home, school and work-place.

#### 3) Regarding Management:

There are some general management principles, not TB specific, that we found useful.

- a. Leadership is crucial. Leaders set the tone, can inspire staff, and look ahead to see what future challenges are.
- b. There needs to be a strong sense of mission.
- c. Investing in staff will pay the program back many times over: hiring the appropriate staff, training and supervising them, as well as allowing for their professional growth.
- d. Everyone from the clerk to the director should be held accountable for results.
- e. Results should be analyzed and reviewed on a consistent basis, and new projects and initiatives should be developed from the findings.

#### *The road ahead*

The work is not yet done in New York. We need the following: 1) to address the needs of the foreign born, with their different cultural, linguistic and belief systems; 2) to improve our collaboration and coordination with the private sector; 3) to remember the U-shaped curve of concern, so we maintain the infrastructure of TB control; and 4) to maintain the sense of urgency and mission that helps to fuel the work.

#### **Conclusion**

We have come a long way, but there is still much to accomplish. What are the lessons for Japan? Fortunately, the goals of TB control are the same everywhere: that persons with TB are diagnosed promptly and treated until cure. That these patients are cured is a concern for all of us, for we are all connected by the air we breathe. Each person cured of infectious TB eliminates a source of other cases, safeguarding the rest of the community.

To come full circle from the beginning of this presentation, I conclude with the words of Hermann Biggs, whose principles for TB control and thoughts are still relevant today: "Public health is purchasable. Within natural limitations a community can determine its own death rate." We did it in NYC. And if it can be done there, Japan can do it too.

## 第76回総会特別講演

## 成功を取めたニューヨーク市の結核対策10年

Paula I. FUJIWARA

要旨：1970年代の後半から1980年代にかけて、ニューヨーク市の結核患者は増加が始まり、1990年代初期には3倍にも増加した。この結核再興には4つの要因があった。すなわち、1) 予算措置などへの行政的な取り組みの低下による結核対策組織の弱体化、2) HIV流行、3) 院内感染対策の不備、4) 高蔓延国からの移民の増加。しかし、強力な対策努力により、1992年から1999年にかけてニューヨーク市の結核は著しく減少した。新患者数は62%、多剤耐性患者も93%減少した。米国生まれの成人患者、特にHIV感染の大きい青年から中年(25~44歳)では81%も減少した。患者中のHIV感染者の割合は34%から22%に減った。一方、外国人の比率は18%から58%に増えた。この結果をもたらすためには、ニューヨーク市はDOTS戦略の原則を採用した(もちろん当初はDOTSという表現を用いていない)。またDOTSとDOT(直接監視下治療または直接服薬支援)は異なる。DOTSはDOTをその一部とした結核対策5原則からなる総合的パッケージを指す。すなわち、1) 強い政治的意志(ニューヨーク市保健衛生局長の強い支援、国・州・市当局へのロビー活動と予算の拡大、大学教授連への働きかけによる変革中心者としての支援等)、2) 菌検査サービスの充実(検査結果報告の迅速化、感受性検査の義務化、菌検査汚染動向の把握等)、3) 抗結核薬の安定供給(開業医もDOTを条件に薬が支給される、多剤耐性患者のため標準方式遵守を条件に新治陰薬を許可)、4) 定期的対策評価(全患者の治療コホートを四半期ごとに検討する評価会の開催、受持スタッフが対策責任者〈結核課長〉に報告。会の最後には次回までの目標の設定。1患者に対する接触者検診者数=接触者検診指数の検討等)。1992年から1999年までに対策の質は確実に改善されたとと言える。

キーワード：ニューヨーク市、結核対策、DOTS、DOT