Suppression of Beijing Blood Safety Conference, Detention of Activist Wan Yanhai and Related Blood, Hemophilia, HIV/AIDS and Human Rights Issues

The second conference on blood safety, AIDS, law and human rights, organized by Beijing AIZHIXING Institute of Health Education and scheduled to be held in Beijing from 25 November, has been cancelled due to government pressure. AIZHIXING encouraged all regions to hold meetings and design representatives to attend the conference. People living with HIV/AIDS were represented and the summit raised participation of legal experts and social organizations. Over 70 people, including Chinese representatives of AIDS organizations, legal and medical experts and human rights activists were invited to the event, a circumstance which seems to have put the government on guard.

On Friday 24th, on the eve before the conference, leading activist and head of Beijing AIZHIXING Institute for Health Education Wan Yanhai was summoned to the building management office by 4 men who identified themselves as police officers from the Beijing Public Security Bureau. After a few questions, Wan Yanhai called other staff members and asked them to cancel the blood safety conference and arrange for the return of all the participants. After that, he was taken away and detained for three days. His mobile phone was switched off and he was unable to make contact with friends, family and colleagues.

The first conference on blood safety, law and human rights was organized by Beijing AIZHIXING Institute for Health Education in November 2005. It raised issues related to blood safety, compensation for victims of HIV/AIDS/HBV/HCV and their families, law and human rights. The three main outcomes of the conference were as follows.

First, request the State Council and the Ministry of Health to set up a committee for the investigation of blood borne HIV infection through the use of blood products during the period from 1987 to 2005 and make public the situation regarding the epidemic. Legal experts, non-governmental organizations and victims of the disease should participate in the process of election. The objectives of this committee are to establish and make public the true facts about the epidemic, identify responsible parties and put forward issues of compensation, aid, policy and human rights protection.

Second, urge the Chinese government to make use of the media to promote voluntary HIV/HBV/BVC screenings among those people having had contact with blood products between 1987 and 2005.

Third, set up a working committee for human rights advocacy and compensation for the victims. Ten main representatives infected with HIV/HBV/HCV were elected and AIZHIXING Institute for Health Education was designed as the secretariat office of the committee.

Fourth, request the Bureau for the AIDS Cure and Prevention, the Ministry of Health and the Public Security Bureau to seek liability and to make sure that people infected with HIV/AIDS as a result of blood contact are treated according to the law.

A report on the outcome of the conference was sent to the State Council, the Supreme Court, the Department of Justice and other relevant departments as well as to the UN and the media.

The agenda for the second conference was to provide a platform for people infected through blood products and social organizations to share their experiences, go back to existing problems, face new challenges, discuss improvements and developments and set up new strategies for the future.

The issue of blood safety is a very serious problem in China. In the 1990s, as a result of the mushrooming of non authorized blood centers, non disinfected or illegal blood transfusions and unsafe collections of plasma, China had to face a devastating amount of HIV/AIDS and Hepatitis infections.

The problem of HIV/AIDS and Hepatitis infection has also affected people suffering from hemophilia. According to incomplete statistics, China currently has 60-70 thousand hemophiliacs. The treatment of this disease demands continuous blood transfusions. Before 1995, the Shanghai Institute of Biological Products, the biggest center of production of the factor VIII needed for the treatment of hemophiliacs, was responsible for producing and selling not reliably disinfected blood products and failed to report on the situation after it was found out, thus leading to many more chain transmissions of HIV/AIDS and Hepatitis from hemophiliacs to their families.

In July 1995, the Ministry of Health issued a notice prohibiting the produce and use of non disinfected blood products. This regulation stated that "clotting blood products produced in China before 1994 were not disinfected and represent an extremely high danger of spreading blood-boned infectious disease" (Hepatitis and HIV/AIDS).

The physical and psychological strains caused by the disease itself, whether it be hemophilia, Hepatitis or/and HIV/AIDS, are only some of the difficulties the victims have to face. Courts often refuse to hear litigations for compensation, and when they do, victims often have to wait too long for the trial. In other occasions, the justice fails to apply the sentence after the issue of the verdict.

Since 2001, the Shanghai municipal government has offered compensation to hemophiliacs infected by products sold at the Shanghai Institute of Biological Products. They now have free access to HIV screening, treatment, factor VIII, 1000 RMB monthly subsidy as well as 10,000 RMB compensation for those hemophiliacs suffering from HIV/AIDS. Moreover, relevant departments have carried out a systematic follow up of the situation of the sufferers. However, while blood products produced by the Shanghai Institute of Biological Products were used by people from all over the country, this compensation was only made available to Shanghai residents.

International organizations have called for the need to provide more space for the operation of

NGOs in China as they have easier access to high risk and marginalized populations. However, the recent incident involving Wan Yanhai not only shows that such petition has not been paid much heed to. It also raises questions about the government's commitment to be more open about the handling of the AIDS epidemic. Wan Yanhai is not the only AIDS activist detained by police authorities. Compared to others, he can be considered as lucky.

On 24 October 2006, three hemophiliacs were arrested in front of a hospital in Shanghai. The following day, the well known leader of the Chinese Hemophilia Association Kong Delin was detained by the Shanghai authorities. All of them had recently raised issues regarding the protection of the rights of hemophiliacs. Beijing AIZHIXING Institute made an appeal for their immediate release. Kong Delin was released on 30 November, 36 days after his detention, but the remaining three hemophiliacs are still missing and there has been no update on their condition and whereabouts till today.

It is very hard to tackle the situation regarding blood trade in China since it is impossible to reach an estimation of the number of people infected with HIV and Hepatitis as a result of this practice. Whereas China will still needs many years to completely eradicate this problem, the issue of hemophiliacs has more clear boundaries, is easer to tackle and immediate action should be taken to redress the situation.

At present, hemophiliacs infected with HIV/AIDS and Hepatitis do not receive satisfactory treatment and compensation. Hemophiliacs living with HIV and Hepatitis suffer from serious liver deterioration, a circumstance which aggravates their bleeding symptoms, greatly increases the frequency of bleeding and increases the number of units of clotting factor needed. The free medication and treatment made available to HIV/AIDS patients by the government since 2003 is not suitable to hemophiliacs. In addition to a weak immunity system, hemophiliacs are prone to develop various syndromes such as malformation, impaired mobility and bleeding. Free treatment for these conditions is not available. Besides, the government does not provide free treatment for Hepatitis C. This means that the burden of those hemophiliacs is greater than that of the average person living with HIV/AIDS. There is very little awareness of the difficulties they face in their daily life, not only with regard to treatment and compensation, but also with regard to not being able to work and study and to the burden this represents for themselves and their families.

Hence the importance of an urgent call to address the above mentioned issues. Here are the main points which need to be addressed:

- 1. Target the particularities of the hemophiliac community, consult other countries' practices and include those individuals with no access to clotting factor within the bounds of handicapped people.
- 2. Bring hemophiliacs into the social security system.
- 3. Establish strategic reserves and import clotting factor so that hemophiliacs, under crisis periods, can obtain clotting factor, and thereby protect their lives.
- 4. Establish a blood transfusion and blood product safety system to guarantee the safety of hemophiliacs using blood and blood products.

- 5. Raise social awareness and pay special attention to hemophiliacs, who, because of continuous use of blood products, are under a higher risk of contracting HIV/AIDS, HCV, and other viruses.
- 6. Timely treat and assist hemophiliacs who have contracted HIV/AIDS and hepatitis C as a result of using blood products.
- 7. Fulfill the obligation, along with relevant state departments, to inform society about the risks of contracting HIV/AIDS via blood products. In addition, provide free testing for patients who have used blood products and for their relatives and dependants, investigate the situation of hemophiliacs contracting HIV and seek liability. Create a medical treatment express path for hemophiliacs; solve hemophiliacs' general hospitalization problems.
 - a. Set up a full time polyclinic doctor to direct treatment for hemophiliacs
 - b. Supply public hospitals with clotting factor
- 8. Advise the government to expedite the introduction of suitable alternative medications for hemophiliacs with HIV/AIDS since the current range of medications available is very limited and produces many side effects.