Information for new participants

Monitoring HIV infection in the Netherlands

The Stichting HIV Monitoring (HIV Monitoring Foundation)
Since 1 January 2002, the Stichting HIV Monitoring (SHM) is responsible for the collection and analysis of data obtained from HIV patients who are being followed-up in any one of the Dutch HIV Treatment Centres. The data is encoded and stored anonymously in the national database, which is managed by the SHM. Data are used for both scientific and policy oriented research.

In doing so, the SHM contributes to increasing our knowledge of the epidemic and the course of the HIV infection. Research findings are published regularly and result in recommendations aiming at doctors and patients, as well as the Government and the National Health Service.

Monitoring of the course of the HIV infection is considered as being part of HIV patient care. A better understanding of the course of the HIV infection, the effects and side-effects of anti HIV treatment and the development of resistance to the medication in the long term will benefit patients and furthers to the development of new diagnostic and treatment methods.

Being part of patient care implicates that collecting data on your diagnosis and the course of the HIV infection will be a regular part of the checkups with your specialist physician, although at any time you can opt out. Taking a blood sample and storing plasma for further laboratory research in later years are also part of the standard HIV/AIDS patient care.

Background
Following the introduction in July 1996 of a number of new antiretroviral drugs (including the so-called HIV protease inhibitors), the Dutch Minister of Health, Welfare and Sport commissioned ATHENA, a research project into the effects of treatment with combination therapy (HAART). It appeared that most patients benefited from HAART treatment. The number of people diagnosed with AIDS and of those dying from HIV and AIDS dropped dramatically.

The amount of HIV in the blood of people receiving HAART treatment decreased significantly and at the same time, there was an increase in the number of CD4 cells, indicating an improvement of the immune system. However, as with other forms of intensive therapy, some patients developed serious side effects. On top of this, not all patients responded to HAART; the treatment failed in a number of cases. Although the therapy was effective for many patients infected with
HIV, the side effects, resistance and failure regularly forced patients to change their medication.

Based on the results form the ATHENA cohort it was recommended to regularly monitor HIV in the Netherlands as a part of the care. Infected patients receiving HAART treatment were also to be included in the monitoring programme. All new cases of HIV infection were to be registered such that the HIV epidemic in the Netherlands could be closely followed. Moreover, it was recommended to continue on therapy adherence and to determine drug resistance and drug blood concentrations in all patients receiving treatment.

The Health Minister accepted all these recommendations and so since 1 January 2002, data is collected for all people infected with HIV who visit HIV Treatment Centres in the Netherlands, irrespective of the type of treatment they receive. The course of the HIV infection in patients who have not started treatment is also being actively monitored. In addition, information is correlated on new infections, i.e. people diagnosed with HIV for the first time.

Pregnant women and children
The SHM has devised a special form of registration to ensure that the health of children infected with HIV is closely monitored. With prior consent, data relating to children can be linked to the data on their mothers. As soon as children are referred to a paediatrician in one of the four paediatric HIV/AIDS clinics in the country, mothers are asked whether they would object to this form of registration. If required, the SHM can also monitor the health of children at risk of becoming contaminated with HIV because their mother or father, for example, is infected.

Storing plasma for research
In certain cases, the blood sample you give will be stored in the hospital in the form of plasma to be used for scientific research. Should this be the case, your treating physician will always ask for your prior consent. In consultation with your specialist, you will be notified of the findings of any research for which your plasma has been used. This is particularly important if these findings have implications for your treatment.

HIV monitoring and your privacy
The information that your specialist collects on the course of your infection will be recorded in the SHM national database under a unique code, with no mention of your name or address. Your blood plasma will be stored under the same code. The only people with knowledge of this code are you, your specialist and the data administrator. The data administrator is a member of your specialist's treatment team and is subject to the same obligation to maintain medical confidentiality. This will ensure that your privacy is protected. You are always at liberty to block the monitoring process by formally objecting to the registration of your medical record.

All activities undertaken by the SHM are of a scientific rather than commercial nature. The SHM is funded by the Ministry of Health, Welfare and Sport. The SHM executive board is made up of representatives from the HIV Association of the Netherlands (patient interests group), the Netherlands Association of AIDS Specialists, the Academic Hospitals Association, the Dutch Hospitals Association, Dutch Healthcare Insurers and the Dutch Municipal Healthcare Services. The SHM is based in the Academic Medical Centre in Amsterdam. More detailed information can be found by visiting www.hiv-monitoring.nl. Please contact us during office hours if you have any further questions.

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