



Information for new participants

HIV-exposed children that received a short-term treatment with HAART [highly active anti-retroviral therapy]

Monitoring of the HIV-infection in the Netherlands

The Stichting HIV Monitoring [The 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.

HIV-exposed children

The SHM collects data from HIV-infected children on the diagnosis and the course of their infection. The health of children without an HIV-infection, but born from HIV-infected mothers, is being followed, too. With these children, the long-term effect of the short treatment with HAART during and right after the delivery is examined.

In order to be able to follow these children's health optimally, the SHM set up a special form of registration. In these cases the child's data are linked to the mother's data, if a 'no objection' is given. The paediatrician will always ask the child's parents and/or carers for permission to collect data.

Storing plasma for research

In certain cases, the blood sample that is taken from your child will be stored in the hospital in the form of plasma to be used for scientific research. Should this be the case, the paediatrician will always ask for your prior consent. In consultation with the paediatrician you will be notified of the findings of any research for which your child's plasma has been used.

HIV-monitoring and your child's privacy

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

Stichting HIV Monitoring [HIV Monitoring Foundation]

Academic Medical Centre, University of Amsterdam
Meibergdreef 9, 1105 AZ Amsterdam
Telephone 020-566 41 72
Telefax 020-566 91 89
E-mail hiv.monitoring@amc.uva.nl
<http://www.hiv-monitoring.nl>