





The I-DSD Registry

(Information for Children Less Than 14 Years Old)

- If you have any difficulty reading this, please ask your parents to help you. They will know much more about this.
- A number of doctors and scientists are trying to find out more about the kind of condition which you have. It will help us all to find out how the body develops. It will also help us to improve how we look after children like you. As there are not many children like you, it can be very difficult for these doctors to do their work.
- Your hospital doctor would like to put some of your details into a computer in a special way so that these other doctors can find out more about your condition. But, nobody, except, your own hospital doctor can tell that the details in the computer are yours. If these other doctors want to find out more, they will need to talk to your own hospital doctor first.
- Your hospital doctor will discuss this with your parents too.
- Your hospital doctor will be very happy to answer any questions you have.
- Do let your parents and your doctor know if you do not want this information on the computer.
- If you do not want to do this it will not change any of the treatment you are getting from the doctors.
- Thank you for reading and listening to this.
- When you turn 16 years old your hospital doctor will send you a more detailed leaflet to read.
- The name and address of the hospital doctor who has supplied your information is as follows:-

{Local clinician} {Local Hospital Address}