

## EuroDSD WP05-3 Urine Collection and Instruction Sheets for Parents

### EURO DSD Instruction sheet for 24-h urine nappy collection

#### Informations and instruction sheet for Parents

We would like to measure the amount of steroids (hormones) that your child produces over a period of 24 hours. To make this easier for you and your child, we suggest that you collect the nappies of your child over a period of 24 hours. We are able to extract the urine from the nappies and measure the hormones in it.

#### **How to collect the nappies**

Clean the child in the normal way. Do not apply lotions or creams to the skin. Please use the same type of nappy throughout the 24-hour collection period. You will also need a bin bag for placing the nappies in it.

Take a clean nappy and close in the usual way. This is *the starting time*.

At each change, if only wet („wee“ only), place the nappy in a black plastic litter bag and fold the top down. Please use the attached collection sheet to note the time-point when nappies were changed and if they were discarded or included in the collection.

If the nappy is soiled („poo“), discard the liner and place only the napkin in the bag. At the end of 24 hours, take off the last nappy and add it to those in the bag. This is the *end time* of the collection.

Don't worry about the odd stain of poo, but please do not include significantly soiled nappies.

If your child starts to produce lots of poo, wait a few days and then start collecting again.

Once the 24 hour collection is finished, please tie the bag and attach a luggage label with string (adhesive labels tend to fall off). Note your baby's name, date of birth and date of collection on the collection sheet.

The sealed bag may be kept cool for 1-2 days in the fridge or preferably should be frozen at -20°C (i.e. could be kept in a drawer of your freezer) until you have time to bring it to hospital.

When you bring the nappy bag to your doctor, please also bring a dry, clean nappy of the same brand, which we need for comparison.



EuroDSD Patient ID code \_\_\_\_\_ (completed by doctor)

## Urine Collection Sheet (For children with nappies)

Name of Child: \_\_\_\_\_

Assigned sex (please tick):  boy  girl  not assigned

Date of Birth: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Day Month Year

Brand name of nappies used for collection: \_\_\_\_\_

Size/age group of nappies used for collection: \_\_\_\_\_

### General considerations:

- 1) We prefer ideally a 24-hour urine collection (at least 12 hours).
- 2) All nappies suitable for collection must be kept in a plastic bag and stored in a cool place/fridge, ideally in a freezer.

### Nappy collection:

Please wait until your child has a bowel movement. Throw this nappy out and note the time. This is the **starting point** of your 24-hour urine collection:

**Start** of collection: Time (24hrs) \_\_\_\_:\_\_\_\_ (e.g. 07:00, i.e. 7 a.m.) Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
Day Month Year

### Number of nappies collected:

Please note each time during the day when a nappy has been taken off, **tick the box as appropriate** and follow the instructions above:

- 1.) Time \_\_\_\_:\_\_\_\_  
 poo in the nappy ?  
    → discard it  
 wet nappy ?  
    → put it in the plastic bag for collection
- 2.) Time \_\_\_\_:\_\_\_\_  
 poo in the nappy ?  
    → discard it  
 wet nappy ?  
    → put it in the plastic bag for collection
- 3.) Time \_\_\_\_:\_\_\_\_  
 poo in the nappy ?  
    → discard it

- 4.) Time \_\_\_\_\_:\_\_\_\_\_
- wet nappy ?  
→ put it in the plastic bag for collection
  - poo in the nappy ?  
→ discard it
  - wet nappy ?  
→ put it in the plastic bag for collection
- 5.) Time \_\_\_\_\_:\_\_\_\_\_
- poo in the nappy ?  
→ discard it
  - wet nappy ?  
→ put it in the plastic bag for collection
- 6.) Time \_\_\_\_\_:\_\_\_\_\_
- poo in the nappy ?  
→ discard it
  - wet nappy ?  
→ put it in the plastic bag for collection
- 7.) Time \_\_\_\_\_:\_\_\_\_\_
- poo in the nappy ?  
→ discard it
  - wet nappy ?  
→ put it in the plastic bag for collection
- 8.) Time \_\_\_\_\_:\_\_\_\_\_
- poo in the nappy ?  
→ discard it
  - wet nappy ?  
→ put it in the plastic bag for collection
- 9.) Time \_\_\_\_\_:\_\_\_\_\_
- poo in the nappy ?  
→ discard it
  - wet nappy ?  
→ put it in the plastic bag for collection
- 10.) Time \_\_\_\_\_:\_\_\_\_\_
- poo in the nappy ?  
→ discard it
  - wet nappy ?  
→ put it in the plastic bag for collection

Please note the time of when you took off the last nappy of the collection (**end point** of your 24-hour nappy collection):

**End** of collection: Time (24hrs) \_\_\_\_\_:\_\_\_\_\_ (e.g. 07:00, i.e. 7 a.m.)      Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
Day    Month    Year

**Please bring the nappy collection to your next appointment at the pediatric outpatient's clinic (should be on the next day after collection).**

Please call Dr \_\_\_\_\_ at \_\_\_\_\_ if you have any questions or concerns.

Thank you for your assistance in this important research !



### EURO DSD Instruction sheet for 24-h urine collection (trained children)

We would like to measure the amount of steroids (hormones) that your child produces over a period of 24 hours. For this, please use the urine bottle provided by your doctor and let your child use it **everytime during one day**. The best thing is to start the collection one day before you have an appointment at the hospital where you can pass the bottle to your doctor. During the collection please store the urine bottle on a cool place and do not expose it to a heater or sunlight.

Please **note the starting point and the end point of collection** (above). Most suitable is to start collection with the first morning wee (which included the urine from the whole night) and to do the last collection before your child goes to sleep.

### Urine Collection Sheet (For trained children)

Name of Child: \_\_\_\_\_

Assigned sex (please tick):  boy  girl  not assigned

Date of Birth: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Day Month Year

**Start** of collection: Time (24hrs) \_\_\_\_:\_\_\_\_ (e.g. 07:00, i.e. 7 a.m.) Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
Day Month Year

**End** of collection: Time (24hrs) \_\_\_\_:\_\_\_\_ (e.g. 07:00, i.e. 7 a.m.) Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
Day Month Year

**Amount** of urine collected \_\_\_\_\_ml