

QUESTIONNAIRE FOR GALACTOSEMIC PATIENTS

Date of collection : ____/____/____

1/5

Family medical history and genetics:

- Year of birth of your mother : ____ Age of your mother's first period : ____
- Your mother's height : _____
- Your mother's education level and occupation : _____

- Year of birth of your father : ____
- Your father's height : _____
- Your father's education level and occupation : _____

- Did one of your parents have fertility problems: mother yes no
father yes no
- Number of siblings: ____brothers ____sisters
- Age and size of your siblings : Sisters : _____
Brothers : _____

- Do you have a parent, sibling or other relative with galactosemia ?
 yes no If yes, which one(s)? _____

- as there been an identified genetic mutation in you or your family? yes no
If so, which one? _____

If you are a woman with Galactosemia, complete below:

- Height : ____ weight : ____
- Age at the beginning of breast development:
____years ____months
- Age of the first period : ____years ____months
- Did the periods appear spontaneously or under treatment?:
 spontaneously under treatment
- Are your periods regular ? yes no
Are you taking a treatment to regularize your periods? yes no
Please specify : _____

- Has an ovarian cryopreservation been performed :
 yes no If so, when : _____

If you are a man with Galactosemia, complete below:

- Height : ____ weight : ____
- Have you had testicular descent surgery?
 yes no
- If so which side?
 left right

- Age at first signs of puberty :
____years ____months

- If you are a woman with Galactosemia, complete below :
- Do you have children? yes no

If you have children :

How many children? _____

Specify the year(s) of birth: _____

- Was the pregnancy(s) spontaneous? yes no If so, how many : _____
- What was the timeframe to get pregnant ?
 <6 months 6 to 12 months 1 to 2 years > 2 years
- Have you had miscarriages? yes no If so, how many ? _____
- Did you receive any medication to get pregnant ? yes no
 If so, what type ? _____
- Have you used in vitro fertilization? yes no
 Number of attempts: _____ Number of successes: _____
- Have you used oocyte donation? yes no
 Number of attempts: _____ Number of successes: _____

If you do not have children :

- Have you ever attempted to get pregnant? yes no
 If yes, answer the following questions:

- For how long did it take you to try to get pregnant without treatment?
 <6 months 6 to 12 months 1 to 2 years > 2 years
- Have you had miscarriages? yes no If so, how many ? _____
- Did you receive any medication to try to get pregnant ? yes no
 If so, what type ? _____
- Have you used in vitro fertilization? yes no
 Number of attempts: _____ Number of successes: _____
- Have you used oocyte donation? yes no
 Number of attempts: _____ Number of successes: _____

- Age of your partner : _____
- Has your partner undergone any special treatment for fertility problems?
 yes no If yes, specify which treatment(s) : _____
- Does your partner have any health problems? yes no If yes, which ones : _____
- Has your partner ever had children from a previous union? yes no
 If yes, number of children: _____

▪ If you are a man with Galactosemia, complete below :

▪ Do you have children ? yes no

If you have children :

How many children? _____

Specify the year(s) of birth: _____

▪ What was the timeframe for the conception(s): <6 months 6 to 12 months 1 to 2 years > 2 years

▪ Do you have an identified fertility problem? yes no

If yes, specify : _____

▪ Have you taken any special treatment for fertility problems? yes no

If yes, specify which treatment(s): _____

If you do not have children :

▪ Did you ever try to conceive a child ? yes no

If yes, answer the following questions:

▪ For how long did it take you to try to conceive without treatment?

<6 months 6 to 12 months 1 to 2 years > 2 years

▪ Do you have an identified fertility problem? yes no

If yes, specify : _____

▪ Have you taken any special treatment for fertility problems? yes no

If yes, specify which treatment(s): _____

▪ Age of your partner : _____

▪ Has your partner undergone any special treatment for fertility problems?

yes no If yes, specify which treatment(s) : _____

▪ Has your partner used in vitro fertilization? yes no

Number of attempts: _____ Number of successes: _____

▪ Does your partner have any health problems? yes no If yes, which ones : _____

▪ Has your partner ever had children from a previous union? yes no

If yes, number of children: _____

To be completed for women and men with Galactosemia :

- Are you undergoing long-term treatments? yes no

If yes, which one(s): _____

- Do you have complications from galactosemia? yes no

Specify the complication(s) with the age of onset (ophthalmic disease, epilepsy, language disorders, motor disorders, etc.....)

Complications	Age of onset
	_____ years _____ months
	_____ years _____ months
	_____ years _____ months
	_____ years _____ months

- Latest intraerythrocytic galactose level: _____ Date : _____

- Have you had FSH, LH, AMH (Antimullerian Hormone), prolactin?

If yes, when and what were the last results?

- Do you follow the recommended diet: yes no

- Do you smoke? yes no If yes, how many cigarettes per day? _____

- Are you concerned by the following risk factors:

	yes	no
Diabetes		
High blood pressure		
High cholesterol		

- Do you have any other health problems (surgeries, accidents, long term medication....)?

- Who are you?

- Level of studies : _____
- Profession : _____

- Marital status: married single married life