Dear parents and guardians,

we are very happy about your participation in our interventionstudy. With that, you help us to learn more about patients and parents knowledge and attitude about possible late effects of cancer treatment.

Please take some time to answer a few questions for us. Your answers will be stored and evaluated without any conclusions on your person.

Thank you very much for your support!

C_Parents_2

Data provider ID: ☐☐

Parents ID: ☐☐ Date of questionnaire completion: ☐☐☐☐☐☐

Personal Data

1

Who is answering the questionnaire?

- ◯ Biological mother
- ◯ Biological father
- ◯ Other female legal guardian (e.g. step, adoptive or foster mother)
- ◯ Other male legal guardian (e.g. step, adoptive or foster father)

When were you born?

Please indicate the month and the year, in which you were born.

Month: ☐☐ Year: 1 9 ☐☐

2

Did anyone discuss with you <u>during treatment</u> the possible late effects of cancer treatment?

	Yes	No	Don't know
Heart problems	◯	◯	◯
Second malignancy	◯	◯	◯
Impaired hearing	◯	◯	◯
Loss of hair	◯	◯	◯
Growths problems	◯	◯	◯
Hormonal problems, including fertility impairment	◯	◯	◯
Mental impairment	◯	◯	◯
Others, specify:			

If yes, with whom you have talked about this?

- ◯ Physician
- ◯ Nurse
- ◯ Any other

If yes, did you have to ask for information on this topic yourself?

◯ Yes ◯ No

3 **Did anyone discuss with you during treatment the possible prophylactic measures to preserve your childs fertility?**

◯ Yes ◯ No ◯ Don't know

If yes, with whom you have talked about this?

◯ Physician
◯ Nurse
◯ Any other

If yes, did you have to ask for information on this topic yourself?

◯ Yes ◯ No

4 **Your child is treated with several types of chemotherapy and maybe also with radiotherapy. How do you estimate the risk of this treatment for a fertility impairment of your child?**

Please tick only one possibility

◯ High risk ◯ Medium risk ◯ Low risk

5 **What risk factors for infertility do you know?**

Tick all you know

☐ Radiation
☐ Total body irradiation
☐ Cranial irradiation
☐ Irradiation of the chest
☐ Pelvic irradiation
☐ Chemotherapy
☐ Therapy with busulfan
☐ Therapy with procarbazine
☐ Therapy with antibiotics
☐ Surgery
☐ Brain surgery
☐ Pelvic surgery
☐ Underlying cancer disease
☐ Age at treatment
☐ Prepubertal
☐ Postpubertal

If your child is a girl... (otherwise continue with question 12)

6 **What signs for fertility do you know?**

Tick all you know

- [ ] Body hair changes
- [ ] Breast size changes
- [ ] Maturation of follicles in the ovaries
- [ ] Hormone changes
- [ ] Clear skin
- [ ] Solid finger nails
- [ ] Menstruation

7 **Which form of hormone replacement do you know?**

Tick all you know

- [ ] Fertility stimulation with growth hormones
- [ ] Oestrogen can be administered in tablet form or by transdermal patch
- [ ] Replacement treatment with LH and FSH

8 **What possibilities of artificial insemination are there?**

Tick all you know

- [ ] Egg cells are fertilized with sexual hormones
- [ ] Sperm cells fertilize egg cells in a test tube
- [ ] A single sperm cell is injected directly into an egg cell

9 **What fertility-preserving measures do you know?**

Tick all you know

- [ ] Freezing of ovarian tissue (Cryopreservation)
- [ ] Freezing of egg cells (Cryopreservation)
- [ ] Cortisone therapy
- [ ] Transposition of the ovaries

10 **Which of the fertility-preserving measures can be applied before puberty?**

Tick all you know

- ☐ Freezing of ovarian tissue (Cryopreservation)
- ☐ Freezing of egg cells (Cryopreservation)
- ☐ Cortisone therapy
- ☐ Transposition of the ovaries

11 **Did your child already use fertility-preserving methods?**

○ Yes ○ No ○ Don't know

If yes, which one?

_____

If your child is a boy… (otherwise continue with question 18)

12 **What signs for fertility do you know?**

Tick all you know

- ☐ Body hair changes
- ☐ Testicular size changes
- ☐ Change of voice
- ☐ Hormone changes
- ☐ Clear skin
- ☐ Solid finger nails
- ☐ Ejaculation

13 **Which form of hormone replacement do you know?**

Tick all you know

- ☐ Fertility stimulation with growth hormones
- ☐ Testosterone can be administered by transdermal patch, gel or injection
- ☐ Replacement treatment with LH and FSH

14 **What possibilities are there for artificial insemination?**

Tick all you know

- ☐ Egg cells are fertilized with sexual hormones
- ☐ Sperm cells fertilize egg cells in a test tube
- ☐ A single sperm cell is injected directly into an egg cell

15 **What fertility-preserving measures do you know?**

Tick all you know

- ☐ Freezing of testicular tissue (Cryopreservation)
- ☐ Freezing of sperm cells (Cryopreservation)
- ☐ Cortisone therapy
- ☐ Stimulation of testicles with LH and FSH

16 **Which of the fertility-preserving measures can be applied before puberty?**

Tick all you know

- ☐ Freezing of testicular tissue (Cryopreservation)
- ☐ Freezing of sperm cells (Cryopreservation)
- ☐ Cortisone therapy
- ☐ Stimulation of testicles with LH and FSH

17 **Did your child already use fertility-preserving methods?**

◯ Yes ◯ No ◯ Don't know

If yes, which one?

_____

18 **Where did you <u>mainly</u> get your information on fertility risks and preservation methods?**

Please tick one or more which you think was/were the most important.

- ☐ From the conversation with the attending physician
- ☐ From the internet
- ☐ From books / magazines / newspapers
- ☐ From the media (television, radio)

19 **Please rate the following statement:**

„I feel sufficiently informed by the information given, to make a decision with my child.“

Strongly disagree	Tend to disagree	Partly agree, partly disagree	Tend to agree	Totally agree
○	○	○	○	○

20 **How strongly do you wish for your child that she / he is able to have children of her / his own?**

- ○ I don’t have such a wish
- ○ A little
- ○ Fairly
- ○ Greatly

21 **Please tell us to what extent each of the following statements applies to you, thinking about children of your child.**

	Not at all	A little	Medi-ocre	Fairly	Greatly
I’m afraid that any child my child may has, would be more likely to have cancer.	○	○	○	○	○
I’m afraid that the cancer of my child may come back.	○	○	○	○	○
I’m concerned about my child’s fertility.	○	○	○	○	○
I’m concerned about fertility-preserving measures side effects.	○	○	○	○	○

22 **Have you recommended your child to have a fertility testing?**

○ Yes ○ No

23 **Have you recommended your child to use fertility-preserving methods?**

○ Yes ○ No

If yes, why?

You can choose more than one answer

- ☐ My child has a high risk of infertility due to treatment.
- ☐ In order to have the additional opportunity for my child to get own children.
- ☐ To have own children has a high priority in our family.
- ☐ Other reason, specify: _____

If no, why not?

You can choose more than one answer

- ☐ My child has a low risk of infertility due to treatment.
- ☐ We do not want to intervene in the natural course of reproduction.
- ☐ Access to the egg puncture through the still intact hymen (vaginal flap) is not acceptable.
- ☐ I am afraid that the cancer of my child may come back
- ☐ I am afraid that any child my child may have would be more likely to have cancer
- ☐ The costs of the freezing and storage of egg or sperm cells are too high for us.
- ☐ The costs of artificial insemination are too high for us.
- ☐ My child is too young to think about having children.
- ☐ Insufficient success rate of artificial insemination.
- ☐ Unforeseeable side effects of artificial insemination.
- ☐ Other reason, specify: _____