About you

Full Name .....

Caregiver Name .....

Contact Number .....

Email Address .....

When (roughly) was your last visit to our Gaucher clinic?

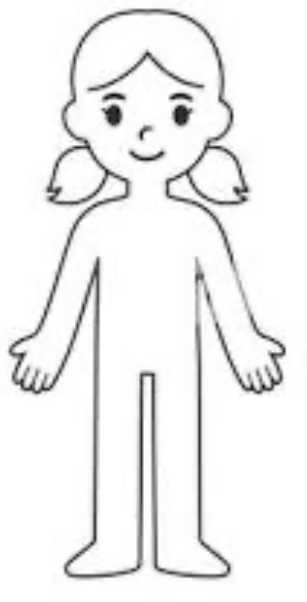
..... / First time

Welcome to our Gaucher clinic!

To make your visit as smooth and helpful as possible, we kindly ask you to fill out this form. Please provide as much detailed information as you can, although it is completely fine if you don't have all the answers. If needed, a caregiver can assist you in answering the questions. You will be able to share this form during your visit.

Thank you!

Symptoms



Pain:

Did you (or your child, if completed by caregiver) have any **pain** episodes since your last visit or in the previous six months?

❑ Yes ❑ No

If yes,

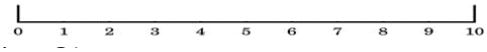
How often?

❑ Virtually continuously ❑ Once a week ❑ More than once a month

❑ More than once a week ❑ Once in two weeks ❑ Once a month

Where?

- circle the part(s) of the body that was/were painful and
- rate how it impacted daily life from 1 to 10
  (1: 'not', 10: devastating pain, 'couldn't do an



Did you (or your child, if completed by a caregiver) need medication to treat the pain?

❑ Yes ❑ No

If yes, what pain medication was used?

_____

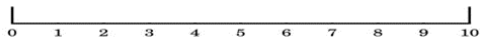
Fatigue:

Do you (or your child, if completed by a caregiver) experience **fatigue** that you can't explain **(tired for no reason)**?

❑ Yes ❑ No

If yes:

- Please rate it from 1 to 10
  (1: no fatigue, 10: extreme fatigue, 'often, with disabling impact')



- If yes, how?

❑ Virtually continuously ❑ Once a week ❑ More than once a month

❑ More than once a week ❑ Once in two weeks ❑ Once a month

- Do you think the **fatigue (tiredness)** may be Gaucher-related?

❑ Not at all ❑ Rarely ❑ Sometimes ❑ Often ❑ All the time

- If receiving Gaucher treatment, do you think the **fatigue (being tired)** is related to the timing of the treatment?

❑ No ❑ After the infusion ❑ Before the timing of the next infusion ❑Other

Bleeding:

Did you (or your child, if completed by a caregiver) have any **bleeding** episodes since the last visit (nosebleed, wound that is not clothing for a longer time than usual, or something else you have noticed)? ❑ Yes ❑ No

If yes, please describe where the bleeding was from, the type of bleeding, how long it lasted, whether intervention was required, etc.

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For Adolescents: Have you started menstruating? ❑ Yes ❑ No. If yes,

At what age did you get your first period? _____ Are your periods regular? ❑ Yes ❑ No ❑ Not sure

How long do they usually last? _____. Do you experience heavy bleeding? ❑ Yes ❑ No ❑ Not sure

.....

GD treatment

Are you (or your child, if completed by a caregiver) currently receiving **medication for Gaucher disease**? ❑ Yes ❑ No

If yes,

- Please describe below (type, dose, frequency, location (at home / ___ km from home, etc.) home nurse? Self-infusion? Use of a central venous catheter, etc.

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- Are you (or your child, if completed by a caregiver) comfortable with the treatment? ❑ Yes ❑ No
- Do you (or your child, if completed by a caregiver) have side effects related to the treatment? ❑ Yes ❑ No
- If yes, please describe below.

.....

Are you (or your child, if completed by a caregiver) currently receiving **non-Gaucher medication**? ❑ Yes ❑ No

If yes, please provide details, including indication, name, dose, and frequency.

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Do you feel that the Gaucher disease-related treatment (clinical visits, infusions, etc.) affects you (or your child, if completed by a caregiver daily life? Like your/ her school (school activities) or meeting others (playing outside, going out with friends) and/or doing what makes you/her happy? Impaire the quality of life?

.....

.....

Wellbeing

Do you (or your child, if completed by a caregiver) **feel depressed**? ❑ Yes ❑ No

Do you (or your child, if completed by a caregiver) **feel anxio**us? ❑ Yes ❑ No

Do you (or your child, if completed by a caregiver) **get sick often?** ❑ Yes ❑ No

If you answered yes to any of the questions above, please detail:

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Do you (or your child, if completed by a caregiver) **exercise**? ❑ Yes ❑ No What types of **exercise(s)** ?

❑ Gym class ❑ Gym - individual ❑ Sport - individual ❑ Sport - team ❑ Run ❑ Swim ❑ Yoga-Pilates ❑ Walk ❑ Other

Are you (or your child, if completed by a caregiver) **allergic** to anything? ❑ Yes (please provide details) ❑ No

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How is your (or your child, if completed by a caregiver) mental health/well-being?

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Final questions

Do you (or your child, if completed by a caregiver) have other medical problems you want to discuss during your visit?

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Is there anything else/concerns you want to share/ask/discuss during your visit?

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What would you like to get from your visit?

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