About **you**

Full Name .....

Contact Number .....

Email Address .....

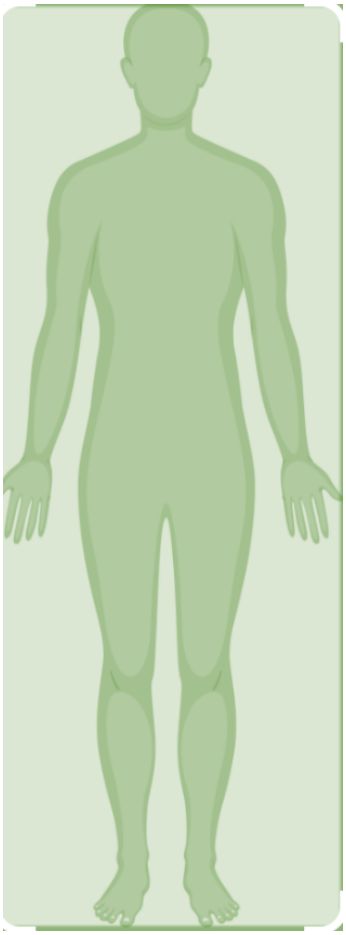
When (roughly) was your last visit in our Gaucher clinic?

..... / 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!

Primary care physician (name and contact) .....

Your symptoms



Did you have any **pain** episodes since your last visit or in the last six months?

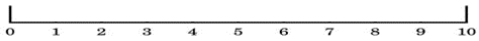
❑ Yes ❑ No

If yes, please

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

Do you experience **fatigue** that you can't explain yourself? ❑ Yes ❑ No

If yes:

- Please rate it from 1 to 10 

  (1: no fatigue, 10: extreme fatigue, 'often, with disabling impact')
- How often do you experience fatigue?
  - ❑ Virtually continuously
  - ❑ Once a week
  - ❑ Once in 2 weeks
  - ❑ Once a month
  - ❑ More than once a month
- Do you think your **fatigue** may be Gaucher-related?
  ❑ Not at all ❑ Rarely ❑ Sometimes ❑ Often ❑ All the time
- If your Gaucher is being treated,
  do you think your **fatigue** is related to the timing of the treatment?

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

Did you have any **bleeding** episodes (for example, nose/mouth bleed, bruises, prolonged bleeding after tooth extraction, etc.) since the last visit? ❑ Yes ❑ No

If yes, please describe (where the bleeding was from, the type of bleeding, how long it lasted, did it require intervention, etc.)

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Treatment

Are you currently receiving **medication for Gaucher disease**? ❑ Yes ❑ No

If yes,

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

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- Are you comfortable with your current treatment for Gaucher disease? ❑ Yes ❑ No
- Do you have side effects related to your treatment for Gaucher disease? If yes, please describe below.

Are you currently receiving **non-Gaucher medication/other treatments, such as physical therapy, nutritional follow-up, vitamins, dietary supplements, psychological support, vaccination, alternative therapy, etc.** ? ❑ Yes ❑ No
If yes, please provide details, including indication, name, dose, and frequency.

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Wellbeing

Do you suffer from **insomnia**? ❑ Yes ❑ No

Do you have **constipation**? ❑ Yes ❑ No

Do you have erectile **dysfunction**? ❑ Yes ❑ No

Do you have urinary **dysfunction**? ❑ Yes ❑ No

Do you feel **anxious**? ❑ Yes ❑ No

Do you feel **depressed**? ❑ Yes ❑ No

Do you have **memory** problems? ❑ Yes ❑ No

Do you have problems with your sense of smell? ❑ Yes ❑ No

Do you have **dental** problems? ❑ Yes ❑ No

If you answered yes to any of the questions above, please tell us more:

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Do you **exercise**? ❑ Yes ❑ No What types of **exercise(s)** do you do, at least weekly?
❑ Gym class ❑ Gym- Individual ❑ Sport - individual ❑ Sport-team ❑ Run ❑ Swim ❑ Yoga-Pilates ❑ Walk ❑ Other

Are you **allergic** to anything? ❑ Yes ❑ No If yes, please provide details

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How is your mental health/well-being? **Does the Gaucher disease affect** your daily life (your work/school/ meeting others/doing what makes you happy)?

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Additional points

Do you 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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