

GAUCHER BEST PRACTICE

Irena Žnidar, Thomas Biegler, Davor Duboka, Gil Faran, Jasenka Wagner

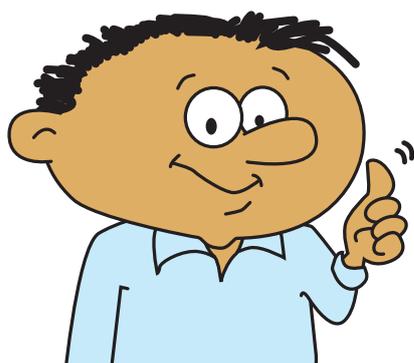
European Gaucher Alliance,
8 Silver Street, Dursley, Gloucestershire, GL11 4ND
United Kingdom

www.eurogaucher.org



Gaucher organizations worldwide have a common voice in the European Gaucher Alliance (EGA), which is an umbrella organization of 45 national organizations.

Treatment and care of Gaucher disease varies in the EGA member countries. There are many examples of good practices in individual countries.



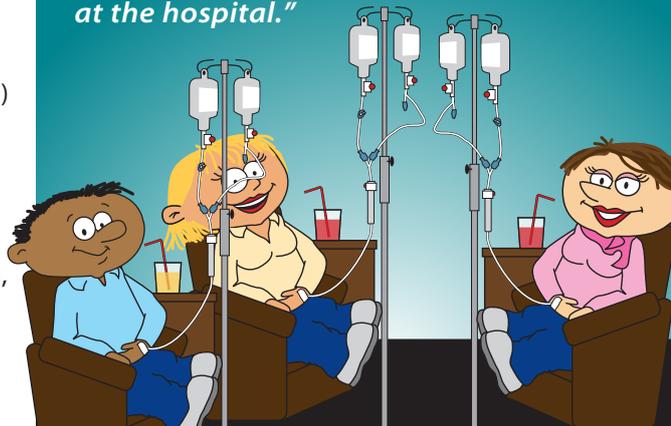
The examples were collected in the year 2015 through a questionnaire with questions related to:

- routine monitoring tests
- enzyme replacement therapy (ERT) (e.g. home treatment, equipment for intravenous infusion)
- substrate reduction therapy (SRT)
- other aspects of the daily life of Gaucher patients (e.g. travelling, privileges, meetings).

131 patients from 22 countries have contributed their answers.

A reader-friendly brochure has been prepared and it will be shared with Gaucher community to learn from in order to improve their daily life with Gaucher disease.

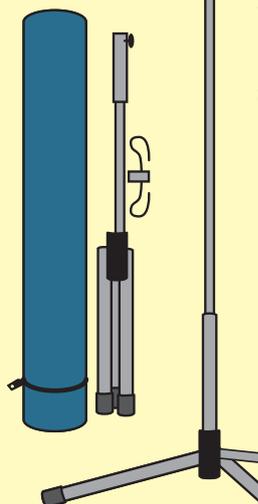
"I meet other Gaucher patients during enzyme replacement therapy at the hospital."



"All Gaucher patients from my country travel the same day to the capital where we all have all monitoring tests. This is also an opportunity to meet each other."

"A telescopic intravenous stand – designed for home treatment, does not remind you on the hospital."

The weigh is 2 kg, when folded it does not take much space (70 x 10 x 10 cm) and is easy to carry."



"The nurse comes to every place in the country even if I am away from home and helps me with the enzyme replacement therapy."



"I pick up the drug at the local pharmacist in my hometown just before having enzyme replacement therapy at home. I bring the drug home in a cool bag and store it in a kitchen refrigerator (the temperature should be 2-8 °C) until having home infusion."

"When I am home alone, I use Y-system, that means I connect both bottles (with the drug and saline for flushing) to the system."

When the first bottle (with the drug) is empty, I only open the flow of the second bottle.

When I don't use Y-system, I ask somebody to change the bottles for me, as this is quite difficult to be done by myself having metal needle in the vein."

