



Living with CIDP - will I need medical treatment forever?

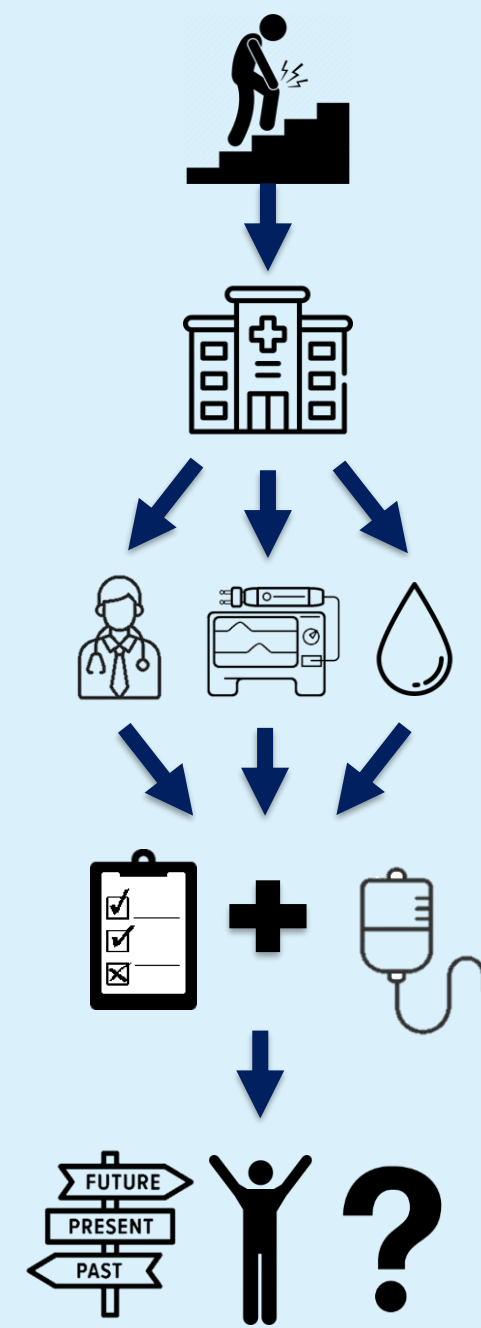
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BACKGROUND & AIM

At the beginning of your journey with chronic inflammatory demyelinating polyneuropathy (CIDP), there is a lot of uncertainty. You go through an period filled with medical tests while you might have felt your symptoms getting worse. Finally, you learn that you have CIDP. Perhaps it was a relief to know what is causing your symptoms. But your diagnosis probably gave rise to new questions. You hear that there are medical treatment options, but no one can predict how well you will recover or for how long you will need it. Some people try different kinds of medications, but still experience a lot of symptoms. We want to know what causes these differences.



Aim: To compare the effect of treatment in people diagnosed with CIDP. Hopefully, this will help in the future to treat each patient in a way that gives them the highest chance of optimal recovery.

DID YOU KNOW...

... that a large group people receive their CIDP diagnosis after first being diagnosed with Guillain-Barré Syndrome?

... that some patients need medical treatment for a long time, but for others it can be successfully stopped?

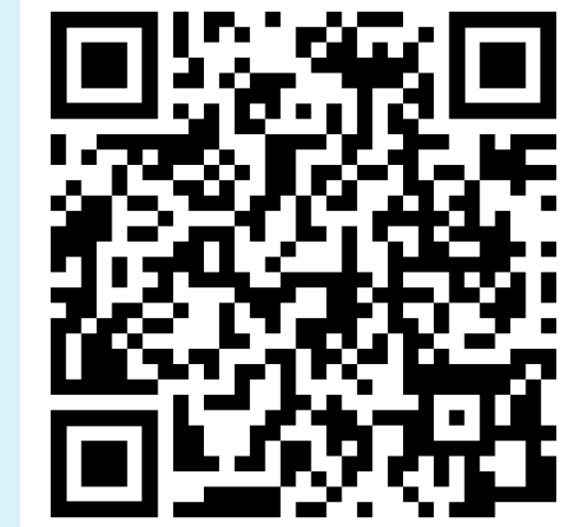
... there is also an ongoing international study called IncBase?
Scan the QR-code to learn more and to see if your center is involved



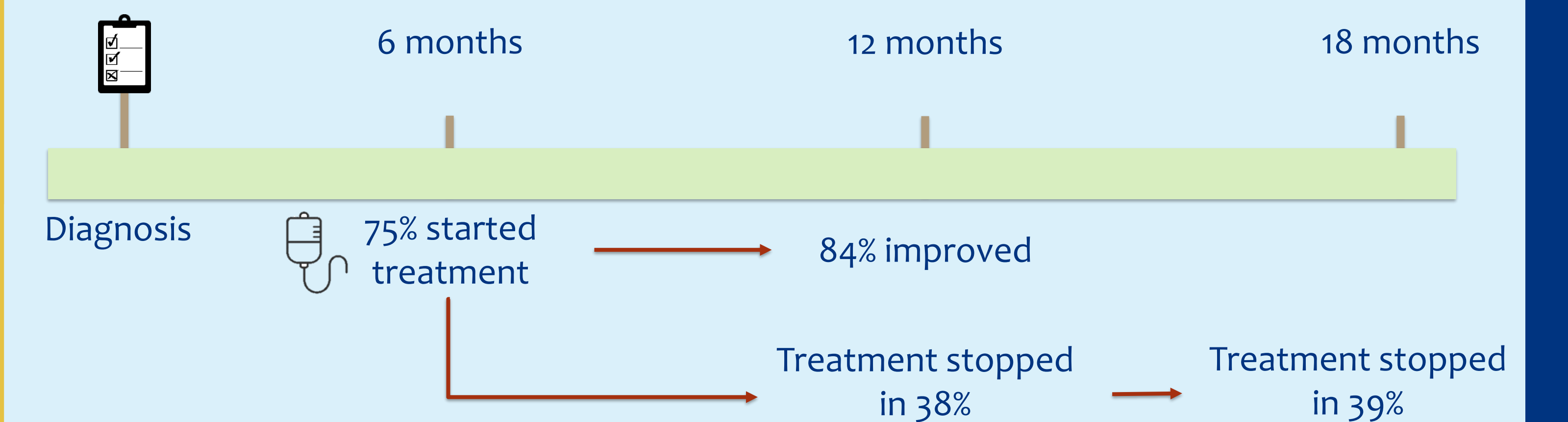
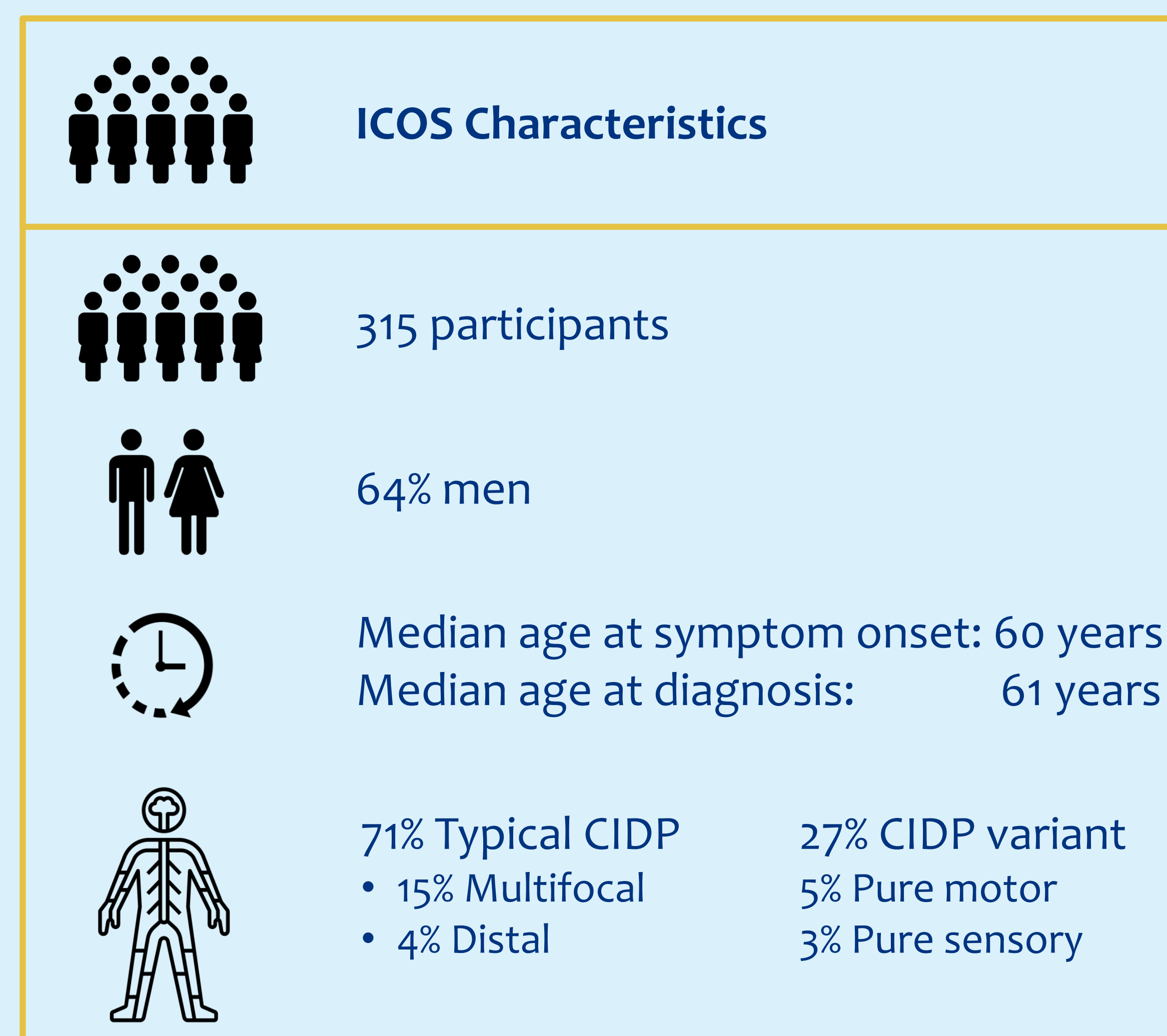
CONCLUSION

- We found a group of patients that only required treatment for CIDP for a relatively short period of time. Now, we want to know if we can find differences between these patients and those who need treatment for a long time. That might help us to estimate how long someone will need treatment before they have even started.

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RESULTS



Within 6 months after receiving the diagnosis, most patients had started any type of treatment (75%). Most of these patients were treated with intravenous immunoglobulins (IVIg). We then checked after another 6 to 12 months how these patients were doing. After starting treatment, 84% of patients had improved. Of these patients, 38% improved in such a way that treatment could be stopped. The percentage of patients that did not need treatment anymore remained stable when we evaluated the period from 12 to 18 months. This indicates that only a small percentage of patients needed to restart treatment after it was stopped.

METHODS

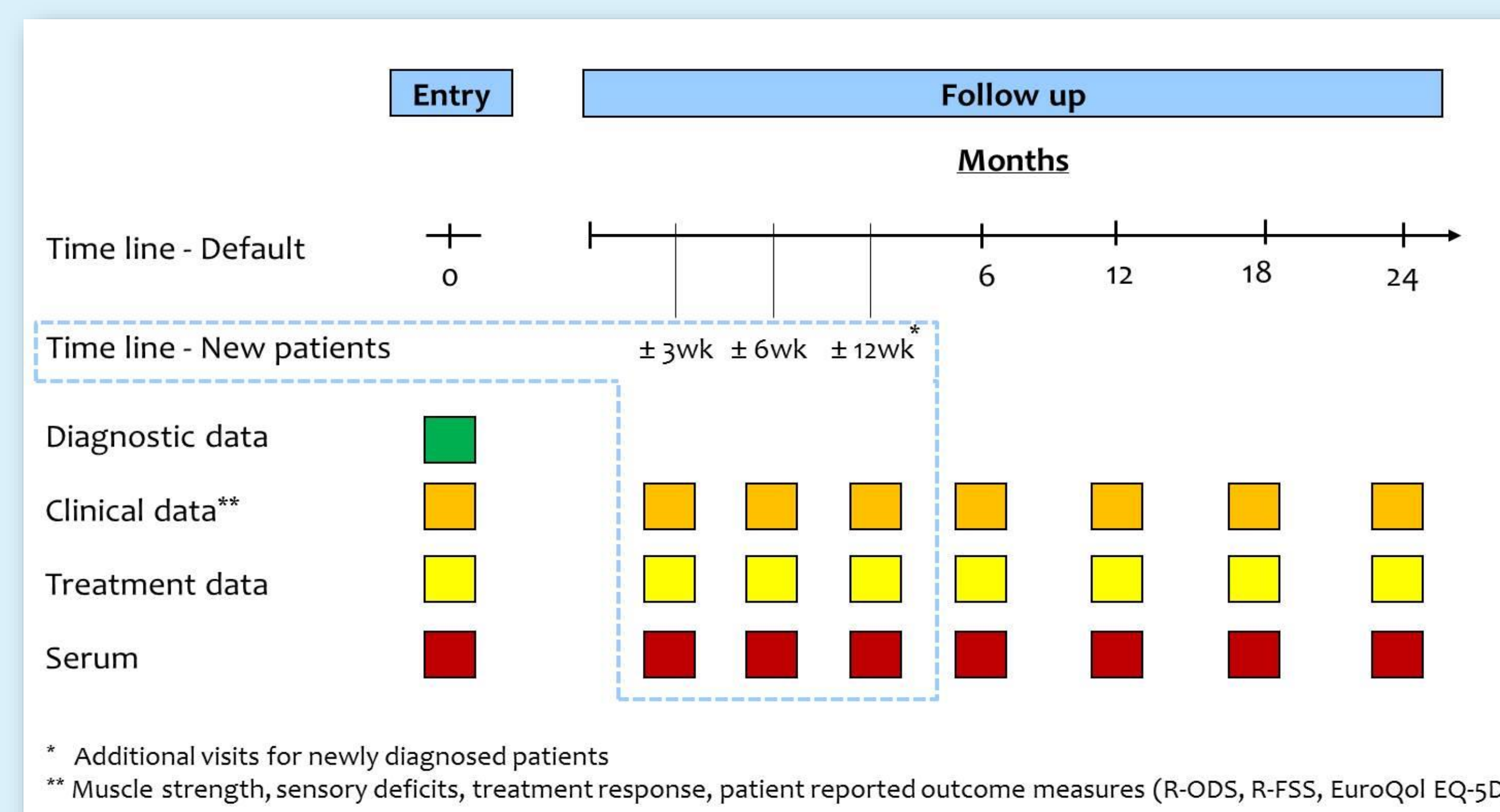
Who can participate?

- Patients with a diagnosis of CIDP, according to the 2010 EFNS/PNS guideline
- Patients must be living in the Netherlands, and visit one of three academic hospitals with expertise in CIDP regularly.

What do we collect?


- When patients visit the (outpatient) clinic, we also collect:
 - Data on current experienced symptoms
 - Data on current treatment and additional support
 - Standardized measurements, such as grip strength, muscle strength and sensory deficits
 - Questionnaires on patient experiences with regard to daily activities, fatigue, and quality of life
 - Blood samples

STUDY DESIGN



WHAT MATTERS TO YOU?

Currently, we ask how well people are able to certain activities. But they also tell us that not everything is relevant to them. **Do you have CIDP and do you want to help us?**

- Look at the list below.
- Which activity should be added to the list? Which should be left out?
- Tell us your ideas by sending an email to cidp.studies@erasmusmc.nl (you can also scan this QR-code )

Run / Remain standing for a long period of time / Dance / Walk outdoors, up to max 0.6 miles / Travel by public transportation / Catch an object (e.g., a ball) / Walk one flight of stairs / Carry and put down a heavy object / Do the shopping / Walk while avoiding obstacles / Bend and pick up an object / Move a chair / Do the washing up / Go to the general practitioner / Wash your lower body / Turn a key in a lock / Take a shower / Make a sandwich / Brush your teeth / Read a newspaper or book / Wash your upper body / Go to the toilet / Dress your upper body / Eat