

The DysNet registry, explained

On 26 August 2026 DysNet's general assembly decided to build a registry of people born with a limb difference, with Health Data Safe as its technical partner. This brief says what the registry is for, what taking part means, how your data is protected, and what it gives the community and you. It is being tested now with the associations in France (Assedea) and Italy (Raggiungere), and opens to other countries after them.

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What the registry is for

No registry, national or European, is dedicated to limb differences. Cases are recorded, when they are recorded at all, in different hospitals and countries, in systems that cannot talk to each other. In large birth-defect studies a cause is found in about one case in five, and usually none for a single limb. That figure moves only when enough cases are described well enough to study.

Between 2007 and 2014, three clusters of babies born without a hand or forearm came to light in France, in Loire-Atlantique, Ain and Morbihan. The investigations found no common exposure, and they met a limit no investigation can repair afterwards: families were questioned years after the birth, from memory. Families who record their situation themselves, from the pregnancy onwards, give the next investigation the data the last one lacked.

THREE OBJECTIVES, IN THIS ORDER Find the next clusters, by bringing the cases families declare together across countries. Keep existing registries alive, by offering the population registries that record our conditions a place to preserve their data if their funding fails. Make registries talk to each other, so that a record moves without being retyped and two countries' figures can be compared.

2

What taking part means

Anyone born with a congenital limb difference can take part, from any country: an adult for themselves, or a parent or guardian for their child, even before birth. The registry works in English, French and Italian for now, and it takes about ten minutes.

STEP 1

Who is taking part?

Yourself, or your child. A parent answers for a child, even before birth.

STEP 2

Sign in or create your account

Your free Health Data Safe account, and your agreement to take part.

STEP 3

Answer the questions

Three questions and two consents, all optional. They save as you go.

You create a free Health Data Safe account (a parent also creates one for the child, from their own) and give one agreement to take part. Then come three questions: the date of birth, or the expected date; the limb difference, which you can search with the words families use or describe in your own words; and where the mother lived at the start of the pregnancy. Two consents follow: to appear on the public map, and to be contacted about research. Every question and every consent is optional, and you can change any answer later.

Your data, and who can read it

DysNet does not store your answers. They stay in your own account at Health Data Safe, a Swiss non-profit foundation under federal supervision, on servers in Switzerland (or in the United States, if you choose that region when you create the account). Data is encrypted when it travels and where it is stored. DysNet holds no patient database: it holds a permission to read what you agreed to share, and nothing else.

Each consent is a separate permission. Your account lists every service that can read your data and records each time it does. You can withdraw any permission in one click: DysNet then stops reading, and what is in your account stays yours, to keep or to delete. Neither DysNet nor Health Data Safe sells health data, and nobody can buy the registry's data or receive it in bulk.

The place of the pregnancy is read by DysNet only to look for clusters, and it is never published. If you agree to the map, it shows a dot blurred over an area you choose (1 to 5 km across, or wider), labelled with the words you choose: the condition, only which limbs, or only that you live with a limb difference. Your dot can be the only one in its area, so choose with that in mind. You can leave the map at any time, and your dot disappears at the next update.

A child's answers go into the child's own account from the start, not the parent's. You hold it for them until they are 18. When they take it over, they review every consent you gave and keep only the ones they choose; your access then ends, and nothing has to move.

Who	What they can see
You	Everything you entered, in your own account. You can change it, download a copy, or delete it all.
DysNet's registry team	Your answers to the three questions, including the exact place of the pregnancy, to count and to look for clusters. Your email only if you agreed to be contacted.
Anyone, on the public map	Only if you agree: a dot blurred over the area you chose, with the words you chose. Never a name, an address or the exact place.
A researcher	Nothing, unless you say yes to their study. Then only the data that study names, for that study.
Your national association	Counts for its country, not your record.
Your doctor	Only what you decide to show, for example the copy you download.
Health Data Safe	It keeps your account and runs the servers. It gives nobody access to your data without your consent.

OPEN ABOUT ITS LIMITS Health Data Safe publishes, requirement by requirement, how it meets the GDPR, Swiss data protection law and the US health privacy rule (HIPAA), and the gaps it still has to close, at compliance.datasafe.dev. It is a self-assessment: Health Data Safe holds no external certification yet, and says so.

WHAT WE ARE CAREFUL NOT TO CLAIM The registry describes the families who choose to take part; it does not count every case in a country. It has no medical board yet: writing a research protocol is a scientific act, and an association will not pretend to perform it. And what families declare about themselves is precious, but it is not clinician-verified data; the two will never be confused.

What it gives the community

Most member associations have never had figures for their own country. The registry gives them: how many people, where, with which condition. With a figure and its source, an association can ask a ministry for a care pathway or for prosthetics to be reimbursed, and be heard. These are the demands DysNet carries at EURORDIS, the European Disability Forum and ERN BOND.

Research on causes needs records that compare across borders. The registry describes every condition with the codes doctors and registries use (ORPHAcode, ICD-10, ICD-11), so that a French record and an Italian one mean the same thing. Once live, it will be listed in Orphanet's European directory of rare-disease registries, where researchers look for data.

The member associations also decide, together with the DysNet board, which studies may be put to families at all. Research reaches the community on the community's terms.

What it gives you

With your doctor

Your condition is recorded with the international codes specialists use, and you can download a copy of everything you entered to bring to an appointment. On dysnet.org, the guide to the conditions and the register of care centres help you find a specialist and prepare your questions.

In research

A researcher proposes a study, and DysNet's member associations and board decide whether it may be put to families. If it is, you see the request in the registry, and by email if you agreed to be contacted: who asks, what for, and which data. You answer study by study. A yes opens that study's data only, and you can withdraw it; a no changes nothing about your place in the registry.

With other families

The map shows where other people with the same condition live, area by area and never by name, so you can see you are not alone and where the others are. The registry does not put families in touch with each other; your national association does, and it is the place to ask.

DysNet, the international dysmelia network, a non-profit association registered in Sweden since 2009, runs the registry, and Health Data Safe contributes its infrastructure in kind. Taking part is free. The registry is looking for its first funders, and it will never be funded by selling data.

Take part, or ask a question

Scan the code or open www.dysnet.org/app. The registry opens first with the associations in France and Italy; your association will tell you when it opens in your country.

The questions and answers, and the full reasoning with its sources, are at www.dysnet.org/registry/. Write to info@dysnet.org.

