

Born with a limb difference, or expecting a child who is?

Take part in the international registry run by the patients' associations themselves.

DysNet, the international network of associations of people born with a limb difference, is building a registry that belongs to the families it describes, not to a hospital or a company. A cause is found in only about one case in five, because cases are spread across hospitals and countries and never studied together. The registry brings them together, with each family's consent.

International · Run by patients' associations · Free · For yourself, or your child even before birth

1 Why it matters

When enough families describe their situation the same way, researchers can see where cases gather and look for a cause. In France, three groups of babies born without a hand or forearm (2007 to 2014) were investigated years later, from memory. Families who record what happened during the pregnancy give the next investigation what that one lacked.

2 Your data stays yours

Your answers stay in your own free account at Health Data Safe, a Swiss non-profit foundation. DysNet reads only what you agree to share, and you can withdraw that permission at any time. Nothing is ever sold, and nothing goes to insurers or employers. You appear on the public map only if you choose to, as a blurred dot: never a name or an address.

3 What it gives you

A copy of your record to bring to your doctor, with the international codes specialists use. A say in research: every study asks you first, and you answer one study at a time. And a view of where other families like yours live, whom your national association can help you meet.

4 What it gives everyone

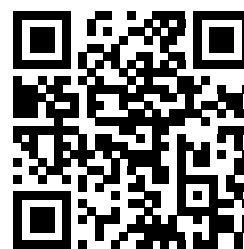
Each country gets its own figures, which most have never had. Associations can show governments how many people need care, prosthetics and research. Researchers get records that can be compared across borders, so the search for causes can start again.

Scan to read more and take part

www.dysnet.org/app

About ten minutes, in English, French or Italian. The registry opens first with the associations in France and Italy, then country by country.

No phone at hand? Ask your national association, or write to info@dysnet.org.



DysNet (dysmelia network) is a non-profit association registered in Sweden since 2009. Health Data Safe, a Swiss non-profit foundation, is its technical partner. This practice does not receive your answers. Leave this sheet for the next person, or take a photo of the code.