When recognition starts with one person

This week's RareFocus looks at how one new Dutch initiative is helping a hidden condition start to be seen.

Sometimes the hardest part of rare disease isn't generating data, it's being seen in the first place.

Arachnoiditis is one of those conditions that hides in plain sight: chronic inflammation and scarring around the spinal cord membranes that can cause severe pain and nerve damage.
It shows up on MRI only sometimes. It is often mislabelled. And for many years, it has had almost no visibility in Dutch healthcare.

That is what makes **Arachnoiditis Nederland** worth noticing.

It began with one person who realised they would have to build the thing they needed.
Before receiving a formal diagnosis, **Marion**, who now leads Arachnoiditis Nederland, had already read the literature, spotted the signs on her own scan, and found international groups that recognised what local systems did not.
When the diagnosis came, there was still no Dutch community, no information, and nowhere to feel understood.

So she made one.

A network built from absence

In April this year Marion started a small Facebook group, *Leven met Arachnoiditis*, along with an Instagram page and a YouTube channel.
At first it was simply a way to find others and share experiences.
But after more visits to clinicians, and seeing how little was known about the disease, she decided to take it further.

By August she had launched a website, **Arachnoiditis Nederland**, to give the condition a clear Dutch-language home: explaining what it is, how it can be diagnosed, and what support exists.
LinkedIn came next, to connect with doctors and researchers and to make the condition visible to a wider professional audience.

Each channel now serves a purpose.
The website informs.
Social media connects.
And together they begin to give the condition a face and a language.

When patients become the educators

What is striking about the website is its detail.
It walks through how arachnoiditis is identified on MRI, including nerve-root clumping, empty sac signs, CSF flow disturbance and Tarlov cysts, and explains why normal imaging does not always mean there is nothing wrong.

It is written for patients, but it is teaching clinicians too.
Not to diagnose online, but to look again.

That is the point. Recognition is not about replacing expertise; it is about showing where expertise needs to grow.

From national silence to European signal

Behind the scenes, Marion is now working to take recognition further.
Because arachnoiditis already has an Orpha code, it can in principle be linked to a European Reference Network.
If accepted, that would trigger studies, guideline development and, ultimately, a shared treatment framework across EU countries.

She has also sent an information flyer to hospitals and clinics across the Netherlands and is reaching out to organisations that support disease recognition to include arachnoiditis within their remit.
It is still early, but the intent is clear: to move from local visibility to European recognition.

Why this small story matters

In rare disease we talk a lot about evidence generation, but we sometimes forget that the first piece of evidence is simply that a condition exists and can be described.
Until then, everything else, from research to access, is built on sand.

Arachnoiditis Nederland, led by Marion, may still be small, but it is already doing something systems often struggle to do: turning lived experience into usable knowledge, and local effort into a growing European conversation.

That is what visibility looks like in its purest form.

Seeing what is already there

Looking at this small network — the posts, the videos, the careful explanations — is a reminder that visibility itself is a kind of evidence.
And sometimes the first step in change is not about frameworks or funding.
It is about one person deciding that silence is not an option.

- **Learn more:**
  Website: arachnoiditisnederland.nl
  YouTube: Leven met Arachnoiditis
  Instagram: @levenmetarachnoiditis
  Facebook group: *facebook.com/groups/698665209194420 (Other)*
- LinkedIn: linkedin.com/in/arachnoiditis-nederland-18a0a0385