What is Superficial Siderosis?

It's a serious, degenerative condition caused by a bleed on the brain or down the spinal cord—this can be a major one but often it's a result of a tiny, constant, silent trickle. After years, often decades, the body breaks the blood down into harmful iron deposits that coat and damage the nerve cells, affecting the way they work.

You can find yourself losing everyday things like hearing, sight, balance and memory.

And it's particularly cruel because you may have already survived something like stroke or trauma.

Thankfully it's exceptionally rare.

Diagnosis has become easier in the past few years and a pioneering study is trialling an experimental drug which seems to be working for some people. When you're first diagnosed, it's a scary and confusing time but at least now there is a little hope.

What we do

A registered charity since 2016 we're working hard to:

Support research: There are still so many questions to be answered. Is it possible to recover after treatment? How many people live undiagnosed? Why is the condition so rare and can it be prevented?

Inform: we're not medical professionals but we do host a unique Q&A and an invaluable webinar with the expert Dr Levy on our website.

Create a safe, listening environment: it's too easy to feel alone. Through our social media groups and events, we provide a chance for our members to talk about their symptoms and everyday lives in a secure and compassionate space.

Spread the Word: this is a cutting-edge field of medicine and there's still so many doctors out there who don't know about it. We want to get people talking: to stimulate more diagnoses, research and treatment



What can you do to help?

Donate: for website running costs, leaflet printing and of course research—every penny counts

Organise: your own fun event—check out our website for more ideas

Become an everyday advocate: get in touch for a batch of free leaflets and share our info with medical staff and relatives.

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