



Hyperhidrosis Research Network



Welcome to the first edition of our Hyperhidrosis Research Network (HRN) newsletter! I'm Louise Dunford and I'm the Director of the Institute of Allied Health Sciences Research at De Montfort University Leicester. Most of my research has been in the field of nutrition, but I have more recently got involved with hyperhidrosis as well, as I was dismayed to see how little research is done, the lack of effective treatments without side effects, and the difficulties that people face trying to access treatments.

In this issue:

- Welcome to the HRN!
- Lynne's Story
- Hyperhidrosis UK
- Research update

The HRN newsletter is in the early stages of development, so please let us know what you would like to see in future editions. Please email us at hyperhidrosis@dmu.ac.uk with any ideas, or if you would like to contribute.

The HRN has been established to bring together people with hyperhidrosis, healthcare professionals and researchers so we can:

- Share new research developments and how you can get involved
- Publicise hyperhidrosis in the media and help to remove misconceptions about it
- Develop an advocacy group so our voices are heard when decisions are being made by the NHS etc.

Lynne's Story

When did you first realise you had hyperhidrosis?

I'm pretty certain it was just after puberty.

How does it affect your daily life?

In every way you can imagine. There is barely a time in the day, except whilst sleeping that you're not aware of it. Without my medication, it can be 0 - 90 degrees and I will probably be sweating. Even at times just watching tv or relaxing it comes from nowhere and overwhelms you.



What treatments have you tried and what has worked for you?

This has been with me now for about 50 years. Doctors never took this seriously at all and I have learnt to cope myself. At the age of 62, moving home, I found a Doctor who listened after showing him a Facebook group I found. His choice of drug for me was the Probanthine. It works for me, simple! I owe him so much.

Have you faced any difficulties in accessing treatments?

I've been ignored, told to take aspirin, paracetamol, change antiperspirant and told to simply live with this. Fifty years is a long time to have to avoid any situation that may become embarrassing. Had I known about this earlier, I'd have been constantly pursuing this treatment.

What advice would you give to someone who has recently been diagnosed with hyperhidrosis?

Just simply, don't give in, keep pushing for recognition that this condition is sheer hell to live with. The answer must not be in just giving out antidepressants, with proper treatment hopefully many of us won't need them!

Are there any websites or online groups you would recommend?

My go to inspiration has been the [Facebook Hyperhidrosis UK support group](#). This is a private group where you can chat away in the comfort of your own space. Also the [Hyperhidrosis UK website](#) has information but is more formal. Haven't found much else as I don't believe it's out there.

Why is it important to you to publicise hyperhidrosis and to get involved with research?

For me it's vital to be involved. Hyperhidrosis has stripped me of so much of what I would term a "normal" life. I read on line recently about someone who refused to have a partner in life as she felt so bad about herself, it broke my heart. This is the tip of a very big iceberg that is out there with possibly hundreds of thousands affected but who never get a diagnosis or help. I'd love to raise awareness.

Hyperhidrosis UK

Hyperhidrosis UK is a well-established and frequently visited website which contains extensive information about hyperhidrosis for patients and healthcare professionals. Detailed information for all the parts of the body affected by hyperhidrosis is provided along with guidance on the options for treatment of these. There is a frequently asked questions section and links to other information sites, blogs and discussion forums which are dedicated to hyperhidrosis. Although aimed at the UK, it receives visitors from all over the world.

- If the answer cannot be found on the website there is the facility to ask questions directly which are answered confidentially and on an individual basis.
- We also produce leaflets for patients both printed and online as well as providing training for healthcare professionals and an electronic newsletter.
- To see more please visit hyperhidrosisuk.org



Richard Oliver from
Hyperhidrosis UK

Excessive Sweating?
HELP IS AT HAND

hyperhidrosisuk.org

What is a clinical trial?

A trial that compares the effect of one treatment with another.

How can I find out about them?

You can ask your healthcare professional if they know of any you could join, or you can search online yourself

How can I find them online?

You can search for trials in the UK at [Be Part of Research](#)

Or for trials all around the world at

Clinicaltrials.gov

Just put hyperhidrosis into the search box. On the clinicaltrials.gov website it is also worth ticking 'recruiting' in the status box under the 'filters' section on the left hand side, as this will take away any trials that are already completed.

Why are there so few hyperhidrosis trials?

There are many complex reasons for this. One is a lack of funding directed to hyperhidrosis research. Another is lack of understanding by the general public about the seriousness of this condition, or even that excess sweating is a medical condition. We hope to address both these issues over time.

How is Covid-19 affecting trials?

In the UK new clinical trials are currently suspended so that research into Covid-19 is prioritised. However, this does not mean that we cannot have hyperhidrosis trials waiting in the pipeline, and studies that don't involve trials, such as survey-based research may still carry on.

Research update

NIHR | National Institute
for Health Research

Some good news, hopefully...

Two groups of researchers in the UK have been carrying out work into identifying research priorities for hyperhidrosis.

Ros Wade and colleagues at the University of York published a scientific review of how effective treatments used in specialist care are. Their review recommended a clinical trial to compare botox against iontophoresis for treating hyperhidrosis of the hands. You can read the full paper here: [Interventional management of hyperhidrosis](#)

In addition, Louise Dunford and colleagues at De Montfort University lead the hyperhidrosis Priority Setting Partnership. With the help of people with hyperhidrosis and healthcare professionals who treat them, they came up with a list of the top ten research priorities. You can read the top ten list here:

[Hyperhidrosis Top 10](#)

Leading on from these studies, the National Institute of Health Research is currently considering commissioning research for a trial for hyperhidrosis. You can read about it here:

[Primary palmar hyperhidrosis](#)

We will keep you updated about its progress!

FINALLY...

If you would like to be featured in the next edition as a person with hyperhidrosis, or you would like to share research news, information about a support group, or anything else about hyperhidrosis with us, please contact: hyperhidrosis@dmu.ac.uk