

Peripheral Neuropathy Study **Imperial College London**

Why did we do the study?

Over the years, many beneficiaries have mentioned that they had pins and needles, numbness and pain. We monitored this trend through our HealthLink system and found it was a common problem. The symptoms described were suggestive of peripheral neuropathy, a disease process affecting the peripheral nerves. These are the nerves in the arms and legs which connect the skin and muscles to the spinal cord.

We decided to look at this further as:

1. The symptoms were distressing and may benefit from treatment.
2. The symptoms could indicate other issues that may need treatment.

We decided to give a grant to a team who work at Imperial College: Dr. Omar Malik and Dr. Richard Nicholas (neurologists who look after people with nervous system problems) and Dr. Alessia Nicotra (a neurophysiologist who uses electrical tests to study nerves).

The study was called 'Evaluation of the peripheral nervous system in patients with thalidomide-induced limb malformations'.

How we did the study

We got ethical approval to do the study from an independent committee that checked that the right procedures were followed to protect those taking part in it.

It was decided to test people who had damage from thalidomide in the arms and had symptoms of pins and needles, pain and numbness. Most of those tested had normal legs and no symptoms in the legs. The Thalidomide Trust identified 17 beneficiaries suitable for the study.

The Imperial College team identified 17 'control' subjects – people of a similar age who had no thalidomide exposure and no symptoms or problems in their arms or legs. Dr. Omar Malik examined all beneficiaries taking part and Dr. Alessia Nicotra performed electrical tests on all people taking part (Dr. Richard Nicholas helped analyse the study and write up the results).

What we found:

a) Nerve compression in the arms.

- 15 out of the 17 beneficiaries examined had features suggestive of a nerve being compressed. This was mainly around the wrist but also in the neck and/or at the elbow.
- The complex anatomy in thalidomide exposed subjects meant that the typical findings of nerve compression were often absent.
- This is likely to make diagnosis of these problems difficult, particularly for doctors who have less experience in this area.

b) Underlying nerve changes in the unaffected legs.

- On average, the electrical response from one of the leg sensory nerves (the sural nerve) was smaller in the beneficiaries than it was in controls.
- Beneficiaries had, on average, feet which were less sensitive at detecting warming than controls.
- Test also revealed differences in some arm and hand nerves, although these could be due to nerve compression.

What do these results mean for you?

- If you have problems with numbness, pins and needles or pain, these might be caused by damage to nerves. It is important that you are seen and examined properly by a specialist. If there is pressure on your nerves, this may be helped surgery. Treatments to help pins and needles and pain arising from nerve damage are also available, regardless of the cause.
- Changes seen in other nerves, which are not obviously compressed, may mean that these were damaged when you were originally exposed to thalidomide. However, this study does not in itself prove or disprove this theory.
- The study results also do not tell us whether the changes in the other nerves are currently causing any symptoms, or whether they will cause any problems with these nerves in the future.

What do these results mean for the Thalidomide Trust?

The Trust will use the findings to:

- Provide information to beneficiaries about the reasons for their symptoms of pins and needles, numbness and pain.
- Provide evidence that can strengthen letters written by the Trust for beneficiaries with symptoms of nerve damage to help a GP make the case for a referral for treatment.
- Provide information to help claims for disability, other benefits and services in the future.
- Inform beneficiaries about how best to manage their symptoms and
- how to get further help.
- Provide information to the medical community and the general public about the problems experienced by those affected by thalidomide.
- Consider what further research is needed to more fully understand the nerve damage in those exposed to thalidomide and how best to treat it.