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The IN Group Joins The Internet

The IN Group has joined the Internet, the world-wide computer web. This allows The IN Group to both receive and provide information globally on the inflammatory neuropathies of Guillain Barr頓yndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).

The association was made possible by the generous support of CSL P/L, the makers of gammoglobulin (their trade name Intragam) which is a favoured treatment for GBS and CIDP. The company provided $3,000 for establishment and $500 for an annual expenditure.

Access to the Internet has been obtained through Vicnet, the agency set up by the State Library of Victoria. Its costs are $100 to join and $15 per month. The latter provides for 20 hours of communication with any excess being at $5 per hour.

"Surfing" on the Internet

Some interesting items have already shown up. In searching "Guillain Barr頓yndrome" I found a report on the first telemedical case for China. A university student in Beijing twice became paralysed with what could have been GBS. A call for diagnostic help was sent out on the Internet: 2,000 replies poured in! The diagnosis turned out to be thallium poisoning.

Then a few days ago I received a message from a Sandra Riley of Massachusetts, seeking information about CIDP from The IN Group - her father, 66 years old, was entering hospital that morning with this diagnosis. I was able to reply that I was airmailing a booklet on CIDP plus our brochure and newsletter. I also gave details of her US body, GBS Foundation International. Sandra was very grateful.

Recent Developments in Inflammatory Demyelinating Polyneuropathy

A report by Dr BRUCE DAY, Consultant Neurologist to The IN Group, following his attendance at the World Conference on EMG and Clinical Neurophysiology held in Japan in November 1995.

Ever since the introduction of therapy such as plasma exchange and intravenous immunoglobulin, people working in this area have been perplexed by the occasional patient who shows a very dramatic and sudden response to such therapy. This response may occur within a day or two even when patients have had symptoms for many years.

A similar response has been seen in another condition know as motor neuropathy with multifocal conduction block and although this condition certainly shares some features with CIDP we are tending to think of it as a separate entity these days.

Recent studies have potentially thrown some insight into the mechanism behind this response. This has lead to speculation that the immune attack on the nerves may not be solely directed against the myelin lining of the nerve but may also be directed against sodium channels* which are responsible for maintaining the propagation of the action potential*. A number of recent studies mainly performed in Japan

have show that patients with Guillain Barr頓yndrome do indeed appear to have antibodies in their serum which are capable of suppressing voltage sensitive sodium channels in experimental models. Some of these patients showed a dramatic response to plasma exchange and when serum was obtained after the plasma exchange it no longer exhibited this ability to block the voltage dependent sodium channels.

The picture has rapidly become more complicated in that some of these antibodies* are capable of interfering with other channels, in particular potassium channels and may produce differing affects depending on activation of complement (another arm of the immune system).
Some of these differing mechanisms may in future help to explain some of the unusual positive symptoms that we see in Guillain Barr頓yndrome such as the rare variant know as "Chor皺 Fibrillaire de Morvan" where patients show wide spread muscle twitching.

Another interesting observation has been that a specific type of these antibodies seems always to be involved in the variant known as Miller Fisher Syndrome. This antibody is also seen in the condition sometimes diagnosed as Bickerstaff's brainstem encephalitis and it is becoming clearer that these two conditions may well represent the same entity.

Obviously further study in these areas needs to be done but it is clear that this is a rapidly evolving area which may well have major consequences on how we diagnose and treat these various conditions.

Glossary

- Sodium channels. Channels in the nerve membrane that allow the passage of sodium ions to generate the action potential.
- Action potential. Mechanism by which electrochemical energy is passed along the nerve.
- Antibody. Protein made by body to combine with foreign material thus activating the immune system.

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