

Raising Awareness of Multiple Sclerosis in India

Mumbai, Bangalore, Hyderabad & Delhi, India, 1-15 February 2007

Multiple sclerosis is not as common in India as in the UK, but it does exist. There are 4000 people with the disease on the MS Society of India's books, with an estimated 40,000 affected in the entire country. Understandably, they struggle to gain the attention of a health system overwhelmed by infectious diseases (including sadly a maternal HIV prevalence of 1%). As an example, consider the workload of the roughly 1000 neurologists serving the one billion population in India. Half see at least 30 patients every day, and 15% see more than 50 patients a day, with average consultation times for new patients being just 15 minutes.¹

Sheela Chitnis' husband developed multiple sclerosis when they were newly-married. It took several years for the diagnosis to be made, during which they experienced all the stress and anguish of perplexing, unpredictable symptoms. This experience led her to found the MS Society of India in 1985 and eventually to attend the MS Life conference organised by the MS Society of the UK and N. Ireland last year. There she met Caron Furnival, and the two planned a delegation from the UK to raise awareness of multiple sclerosis in India. It nearly floundered through lack of financial backing, until Healthcare at Home very generously stepped in as the sole



sponsor. (This company provides home delivery and administration of many different injectables, including the interferons).

So it came about that a team of eight from the UK spent two gruelling and exhilarating weeks delivering lectures and workshops for as few as 40 to as many as 250 health professionals or people affected by multiple sclerosis, in Mumbai (Bombay), Bangalore, Hyderabad and Delhi.

We learnt that unenhanced MRI scans cost about 50US\$ and are accessible for many for diagnostic purposes, although many baulked at the (unnecessary?) request of some neurologists for serial MRI scans. On the other hand, the interferons are theoretically available in India but at a price very few can afford. So neurologists are making imaginative use of cheaper alternatives: such as first-line therapy with mitoxantrone, or intermittent pulsed corticosteroids; reasonable strategies

which would be impossible to test in countries where the interferons are more available. It would make sense for this uncontrolled prescribing to be subsumed within clinical trials, with appropriate financial support, so that the world-wide multiple sclerosis community can learn from them.

It was encouraging to learn that all the patients are offered support and counselling around adjustment issues. However mental health issues such as depression were often ignored, perhaps because of negative stigma associated with psychology or psychiatry. In contrast, spiritual issues were widely acknowledged to be important by patients and health professionals. So too the effect of the illness on the family. That, and the mainstream use of what we would call "alternative medicine" make for an enviable holistic approach to care of those with multiple sclerosis, from which we could learn much.

The group comprised three representatives from the MS Society (Alison Handford, Caron Furnival and their lead physio, Jane Petty), one from Healthcare at Home (Carrie Brown), a MS specialist nurse (Adrienne Cox), an occupational therapist (Denise Middleton), a clinical psychologist (Anita Rose). The neurologist slot was filled by two part timers: Alasdair Coles and Eli Silber for one week each, unable to cope with the pressure of the full timetable!

1. Khadilkar SV, Wagh S. *Practice patterns of neurology in India: Fewer hands, more work.* *Neurol India* 2007;55:27-30.

1st UK Stroke Forum Conference

The Stroke Association hosted the first ever UK Stroke Forum conference at the Harrogate International Centre. The event combined The Stroke Association's Scientific Conference, the National Stroke Nursing Conference and The British Association of Stroke Physicians Conference as a multidisciplinary meeting bringing together over 1000 delegates. Those attending included healthcare professionals, researchers, people with stroke and their carers. The programme featured leading figures in stroke care, research and policy, presentations on the latest stroke research and the inaugural Princess Margaret Memorial Lecture.

The conference opened with an update on the work of the UK Stroke Research Network in the areas of prevention, acute care, rehabilitation, community care and translational research. The Clinical Study Groups, which offer support designing, writing and securing funding for studies as well as identifying studies for adoption as multi-centre trials across the Network, presented their portfolio of ongoing studies.

The second plenary session explored the translation of research findings into good practice. Professor Charles Warlow gave examples where this had happened (e.g. Stroke Units, aspirin) and highlighted barriers (cost, unimpressive findings, inertia and impracticality). He reported that patients' views on what is relevant and valuable to them can differ from statistical results and concluded that good and relevant research both encourages and reduces uncertainty.

As part of the same session Professor Pam Enderby highlighted that focused research trian-

gulating qualitative, quantitative and other evidence is slowly reducing the gulf between researchers and practitioners and improving the translation of findings into practice. Dr Bernard Gibbon discussed the shift in nursing research from the profession-centred 'Carry On' role of nurses, to today's focus on evaluating interventions carried out by nurses in an inter-professional team to improve patient outcomes.

A range of issues in stroke were addressed in the parallel sessions, including imaging, the management of swallowing, communication, cognitive and visual problems. Sara Demain (University of Southampton) discussed how physiotherapists discharge people with stroke. She suggested that the goals and feelings of therapists, the nature of the therapeutic relationship and service constraints shaped the decision to discharge, whilst opportunities for patient participation were limited. Once discharged, people with stroke often experienced feelings of abandonment. Professor Sheila Payne spoke of the need to bridge the gap between stroke rehabilitation and palliative care.

Day two of the conference saw the inaugural Princess Margaret Memorial Lecture taking place with guest lecturer Professor Werner Hacke (University of Heidelberg, Germany). Professor Hacke shared interesting insights into the future of acute stroke care, drawing on international perspectives to set the scene for potential developments. The third plenary session followed, dedicated to the best five research presentations selected through the call for abstracts. These covered motor imagery, insulin and lesion volume, bilateral upper limb training, motivational interviewing

Harrogate, UK, 7-8 December 2006.

and patterns of recovery. The latter was part of the CERISE project, which compared stroke recovery in rehabilitation centres in the UK, Belgium, Germany, and Switzerland. Professor Nadina Lincoln (University of Nottingham) reported significant variation in amount of therapy patients receive. Despite similar staff numbers, UK patients spent significantly less time in therapy and made a worse recovery in comparison to those in Germany and Switzerland.

The conference closed with a session exploring innovations in stroke care. Professor Garth Johnson discussed new technologies in rehabilitation and Professor Sally Byng presented a model to underpin the planning of integrated, comprehensive and sustainable services to meet long-term needs. Professor Martin Dennis focused on the challenge to health care professionals of designing innovative stroke services with limited resources. He concluded that success depends on our willingness to change the way we work to ensure that people have access to and benefit from effective, efficient and equitable services.

For me and the other members of the Stroke Association Rehabilitation Research Centre, the conference provided a platform for networking, sharing ideas, hearing about best practice and discussing challenges. With new contacts and ideas, we are looking forward to next year's event. Speaker presentations are available online at www.ukstrokeforum.org

Dr Dorit Hyndman, Senior Research Fellow at The Stroke Association Rehabilitation Research Centre, University of Southampton, UK.

PREVIEW: The Parkinson's Disease Non Motor Group and the 2nd Annual Meeting on Non Motor Symptoms of Parkinson's Disease

London, UK, 21 April 2007.

A range of non motor symptom (NMS), including dribbling saliva, constipation, depression, sleep disorders, apathy, hallucinations and dementia complicate the lives of people with Parkinson's disease (PD). However, even though the last 30 years have seen enormous advances in the management of the motor symptoms of PD, the NMS complex of PD has remained relatively unexplored. NMS of PD contribute significantly to morbidity and may lead to admission to a nursing home, more than quadrupling the cost of care of PD. Furthermore, recent evidence suggest that NMS such as olfaction, REM behaviour disorder, fatigue and depression may be markers of pre-clinical stage of PD and thus occur in early stage of PD. PDNMS are not well recognised in clinical practice and are recognised as a key unmet need in the NICE guideline for management of PD (Chapter 9).

The international Parkinson's disease non motor group (PDNMG: www.pdnmg.com) was set up by K Ray Chaudhuri after a group of



dedicated neuroscientists met and felt that NMS of PD needs recognition, awareness and assessment tools. The unique feature of this group is its multidisciplinary origin bringing together neurologists, geriatricians, psychologists, sleep experts, nurse specialists, cognitive experts and last but not least, patient group representatives.

We would like to draw your attention to the second meeting of the Parkinson's Disease Non Motor Group (PDNMG) in London, April 21, 2007. We hope this will be an exceptional day with areas of Parkinson's disease management being discussed by an excellent panel of an international faculty of neuroscientists.

We are anticipating approximately 300 people and would be delighted if you could attend and make this second meeting a bigger success. The panel is exceptional, international and will provide an up-to-date summary of various aspects of non motor symptoms of PD that affect the day-to-day life people with Parkinson's, the carers and the treating health-care professionals. The meeting will also address areas of the major unmet need in PD, as addressed by NICE. The day will then conclude with four illustrative cases being discussed in an interactive session.

This will be a whole day meeting on a Saturday and lunch, coffee and refreshments are provided.

The second meeting of the PDNMG is supported by the Parkinson's Disease Society UK and the Movement Disorder Society and made possible by an unrestricted educational grant from Boehringer Ingelheim, Solvay and Britannia Pharmaceuticals. Also the meeting is accredited with 6 CPD points.

PREVIEW: Rehabilitation Medicine Today and Tomorrow: Service models for specialist rehabilitation in hospitals and communities

London, UK, 22 May 2007.

The British Society of Rehabilitation Medicine is hosting its Spring Conference at the Royal College of Physicians, London, on Tuesday 22 May 2007. This will provide an overview of best practice in the provision of specialist medical and multidisciplinary rehabilitation for people with complex needs. Examples from both UK and international service models will demonstrate the role of rehabilitation medicine in a primary-care-led, community-orientated NHS.

The day will deliver updates on modern approaches to service delivery and will identify key criteria for the organisation of services. Questions to be addressed will include:

- How does rehabilitation medicine contribute to national strategies such as 'Our Health, Our Care, Our Say'?
- How much specialist rehabilitation can be delivered in and through community and primary care services?
- What is the role of hospital-based and super-specialist services?

Speakers from abroad will be asked to describe how they have responded to these issues, sometimes with very limited resources.

The Conference will open with a keynote

lecture by Professor Dame Carol Black, National Director for Health and Work (and past President of the Royal College of Physicians, London) entitled 'Health, Work and Well-being: An Inter-departmental Government strategy'. This session will highlight the importance of work and occupation and the role of specialist vocational rehabilitation. Other sessions during the day will

- explore the role of specialist musculoskeletal rehabilitation services and the scope for delivery in the community
- provide overviews of UK service models with international comparisons highlighting challenges and opportunities for service development
- provide reviews of services delivered both by the NHS and by the voluntary sector, and discuss the role of specialist medical expertise in brain injury rehabilitation.

The day will conclude with a panel discussion addressing the question of cost effectiveness of specialist Rehabilitation Medicine, and its



role in delivering current health-care and social policies and a discussion on the future of rehabilitation medicine.

The conference also includes an opportunity for showcasing rehabilitation medicine service models of excellence in the form of posters, for which abstracts

are invited.

The content of the day will be highly relevant to public health specialists, commissioners of specialist services and secondary care services, voluntary sector organisations, consultants in relevant medical specialties such as rehabilitation medicine, neurology, neurosurgery, trauma and orthopaedics and rheumatology. We look forward to welcoming you on the 22nd.

*Professor Christopher Ward,
President,*

British Society of Rehabilitation Medicine.

**For further information visit:
www.bsrn.co.uk**

PREVIEW

17th Meeting of the European Neurological Society

Rhodes, Greece, 16 – 20 June, 2007.

Neurology: Learning, knowledge, progress and the future

Teaching programme:

- Interactive case Presentations: What is your decision?
- Practical sessions in Clinical Neurophysiology
- 22 Teaching Courses covering all important topics in Neurology

The teaching programme of the ENS meeting at Rhodes includes five interactive sessions with case presentations, 22 teaching courses, 1 practical workshop and three practical breakfast sessions.

The interactive sessions on Saturday morning, June 16 encourage attendants to bring cases of interest to the meeting and to discuss clinical presentations by making decisions on diagnosis and treatment. The 21 half-day and one full-day teaching courses are spread out over the entire meeting from Saturday, June 16 to Wednesday, June 20 and aim at providing up-to-date clinical and related scientific information on a broad range of topics covering the main neurological diseases of the central and peripheral nervous systems, neuromuscular transmission and muscle. One teaching course will focus on submission of successful grant applications and the writing of scientific papers. The chairpersons and the faculty have been invited based on their known scientific and clinical expertise on the selected subjects. Three courses are given jointly with the American Academy of Neurology.

Five courses are designated as “integrated courses” and will be part of the scientific programme of the congress, preceded by poster viewing and followed by selected 15-minute oral presentations. One practical workshop on Botulinum Toxin treatment is presented on Sunday, June 17. Practical breakfast sessions on Clinical Neurophysiology will be given on Sunday, Monday, and Tuesday. It is the policy of the ENS teaching programme to interact with attendants as much as possible and instructions to the faculty emphasise the practical clinical relevance of presentations. In order to make the teaching programme as accessible as possible, the interactive sessions and practical breakfast sessions are provided free of charge, and the teaching courses at extremely low cost. Moreover, teaching courses are free of charge for young physicians attending the congress with the “Young Neurologists in Training” offer.

*Prof C Krarup,
Executive Committee.*

Visit the ENS 2007 website
www.ensinfo.com featuring:

- Continuously updated scientific programme
- Online registration as well as hotel & tour registration
- Option to compose your personal congress programme
- Details about the industrial exhibition
- Information about Rhodes



Prescribing information: AVONEX®

Presentations: Lyophilised powder for injection for IM administration containing a 30µg dose (6 million IU) of Interferon beta-1a per vial. Solution for injection in a pre-filled syringe of 0.5ml for IM administration containing 30µg dose (6 million IU) of Interferon beta-1a. **Indications:** For the treatment of ambulatory patients with relapsing multiple sclerosis characterised by at least 2 recurrent attacks of neurologic dysfunction (relapses) over the preceding 3-year period without evidence of continuous progression between relapses. AVONEX® slows the progression of disability and decreases the frequency of relapses. AVONEX® is also indicated for the treatment of patients who have experienced a single demyelinating event with an active inflammatory process if it is severe enough to warrant treatment with intravenous corticosteroids, if alternative diagnoses have been excluded, and if they are determined to be at high risk of developing clinically definite multiple sclerosis (see SPC for further information). Treatment should be discontinued in patients who develop chronic progressive multiple sclerosis. **Dosage and Administration:** The recommended dosage of AVONEX® in the treatment of relapsing MS is 30µg injected IM once a week. AVONEX® lyophilised powder presentation should be reconstituted with the solvent supplied. Treatment should be initiated under supervision of a physician experienced in the treatment of the disease. An antipyretic analgesic is advised to decrease the flu-like symptoms associated with AVONEX® administration. AVONEX® should not be used in children. **Contraindications:** initiation of treatment in pregnancy. Patients with a history of hypersensitivity to natural or recombinant interferon beta or any of the excipients. Patients with current severe depression disorders and/or suicidal ideation. **Precautions:** CNS: AVONEX® should be used with caution in patients with previous or current depressive disorders, in particular to those with antecedents of suicidal ideation. Depression and suicidal ideation are known to occur in increased frequency in the multiple sclerosis population in association with interferon use. Patients treated with AVONEX® should be advised to immediately report any symptoms of depression and/or suicidal ideation to their prescribing physician. AVONEX® should be administered with caution to patients with a history of seizures, to those receiving treatment with anti-epileptics, particularly if their epilepsy is not adequately controlled with anti-epileptics. **Pregnancy and lactation:** Initiation of treatment is contraindicated during pregnancy. Women of child bearing potential should take appropriate contraceptive measures. If the patient becomes pregnant or plans to become pregnant while taking Avonex, discontinuation of therapy should be considered. **General:** AVONEX® should be used with caution in patients with cardiac disease, severe renal or hepatic failure or severe myelosuppression, and these patients should be closely monitored. Routine periodic blood chemistry and haematology tests are recommended during treatment with AVONEX®. Laboratory abnormalities may also occur which do not usually require treatment. **Drug interactions:** No formal interaction studies have been conducted with AVONEX® in humans. Clinical studies indicate that corticosteroids or ACTH can be given during relapses. Caution should be exercised in combining AVONEX® with medicinal products with a narrow therapeutic index and dependent on hepatic cytochrome P450 for clearance. **Side Effects:** The most commonly reported symptoms are of the flu-like syndrome: muscle ache, fever, chills, asthenia, headache and nausea. Other less common events include: **Body as a whole:** anorexia, hypersensitivity reactions, weight loss, weight gain, severe allergic reactions (anaphylactic reactions or anaphylactic shock), syncope. **Skin and appendages:** alopecia, angioneurotic oedema, injection site reaction including pain, pruritus, rash, urticaria. **Digestive system:** diarrhoea, hepatitis, liver function test abnormalities, vomiting. **Cardiovascular system:** chest pain, palpitations, tachycardia, and vasodilatation and rarely arrhythmia, cardiomyopathy, congestive heart failure. **Haematological system:** thrombocytopenia and rare cases of pancytopenia. **Reproductive system:** metrorrhagia and/or menorrhagia. **Nervous system:** anxiety, dizziness, insomnia, paraesthesia, seizures, depression, suicide (see Precautions). Transient neurological symptoms that mimic MS exacerbations may occur following injections. **Musculoskeletal system:** arthralgia, pain, transient hypertonia and/or severe muscular weakness. **Respiratory system:** dyspnoea. Autoimmune disorders, central nervous system disorders and laboratory abnormalities have been reported with interferons. Rare cases of arthritis, hypo- and hyperthyroidism, lupus erythematosus syndrome, confusion, emotional lability, psychosis, migraine and very rare cases of autoimmune hepatitis have been reported with AVONEX®. For further information regarding adverse events please refer to the Summary of Product Characteristics. **Preclinical Safety:** Fertility and developmental studies with a related form of Interferon beta-1a in Rhesus monkeys show anovulatory and abortifacient effects at high doses. No teratogenic effects or effects on foetal development were observed. **Legal Classification:** POM. **Pack Size and UK NHS Price:** Box containing four injections £654. Reimbursed through High Tech Scheme in Ireland. **Package Quantities:** Lyophilised Powder: 1 box containing four trays. Each tray contains a 3 ml glass vial with BIO-SET device containing a 30µg dose of Interferon beta-1a per vial, a 1 ml pre-filled glass syringe of solvent and one needle. Pre-filled Syringe: 1 box containing four trays. Each tray contains a 1 ml pre-filled syringe made of glass containing 0.5 ml of solution (30µg dose of Interferon beta-1a) and one needle. **Product Licence Numbers:** EU/1/97/033/002-003. **Product Licence Holder:** Biogen Idec Ltd., 5 Roxborough Way, Foundation Park, Maidenhead, Berkshire SL6 3UD, United Kingdom. Date of last revision of Prescribing Information: September 2006. Please refer to the Summary of Product Characteristics for further information.

Information about adverse event reporting can be found at www.yellowcard.gov.uk. Adverse events should also be reported to Biogen Idec Ltd., on 08000 286639.

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