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Newsletter No.48 - September 2004

Assessing CIDP Patients & Treatment at Monash Medical Centre

From the address by Dr TIM DAY, Neurologist, Monash Neurology, Monash Medical Centre, The IN Group Public Meeting, held Wednesday 11th August 2004 at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn.

Neuropathy tests - am I getting better?

For many people this is the big question. Sometimes you don't need to be told that you are getting better or not or even worse. Certainly your doctor needs to be convinced that you are getting better.

Ways of checking neuropathy

The first question is why do we do these tests? It is to find the answer to why you are complaining of weakness or numbness or balance problems or pain. Sometimes it is to rule out certain problems.

Secondly, if you have a particular disorder like CIDP or other neuropathies, we need to know if things are staying much the same or getting worse or better? The problem with treatment is that there are all sorts of options to choose from. Apart from Intragam there are many other possible treatments ? some with different side effects, others have greater expense, Intragam in particular has limited availability. Given that it is limited, it is important we try and make the best use of the resource ? use it for people who definitely benefit and not for people who don't respond. Then there is the placebo effect. There is a psychological boost that goes along with any treatment. There was a recent report of knee operation on patients with arthritis. Half the patients had the real operation and half a sham operation. At the end of two years both groups had improved to the same degree. So we need to try and control for this effect.

How do we tell if you have a peripheral nerve disorder?

First we ask you for your symptoms. You tell us about numbness, tingling in fingers, weakness in legs, imbalance, loss of coordination. Now a lot of disorders can cause such symptoms, so we carry out some special tests to identify the signs of these disorders ? hammering on knees to check reflexes, sticking pins to check sensory response, etc. This gives some idea whether things are getting better or worse. Another problem is that it can be difficult to remember from one visit to the next exactly how strong your foot was or the extent of numbness in your toes. Such tests can be augmented by nerve conduction studies, quantitative sensory testing, nerve biopsy; but these can be invasive, take time or may not be suitable for doing on a repeated basis.

The Mayo Clinic specialists have used questionnaires or use a combined grading system of muscle strength, reflexes etc in patients with peripheral nerve disorders, to tell whether they are getting better or worse. A number can be ascribed to each symptom to give a Neuropathy Symptom Score or a Neuropathy Impairment Score. The combination of the two scores can be used to give an overall picture of how things are going. This approach can be very useful in research studies such as diabetic neuropathy, CIDP but it doesn't tell you how you are functioning. What is most important from the

patient point of view is to determine how well you can do things you need to do ? can you dress yourself, can you get out of your chair, can you walk. There are scales to measure these functional needs.

Occupational therapists in conjunction with rehabilitation staff use disability studies. There are a number that have been well tested. There is the Barthel Index which can be used to assess many functions, very useful for patients with stroke, neuropathy and other neurological conditions. There is the Functional Independence Measure, also involving a questionnaire of the patient. The responses are scored depending whether you can or cannot perform various aspects of self-care activities ? eating, bathing, dressing, toileting, bowel and bladder control, ability to get out of a bed or chair, walking, going up stairs. These can be meaningful for day to day activities but there may be other things we want to look at to tell whether you are getting better.

Monash Test Battery

So we decided to devise tests that were easy to do, weren't high tech needing complicated equipment, could be done in a short space of time and were well tolerated. The tests have to be sensitive - to detect meaningful change. These tests have an emphasis on function but combine some of the physical measures.

We considered it important to test both upper and lower limbs. We combine measures of strength, sensation and coordination. We use tests that are tried and true and shown to be useful.

They fall into two main groups ? one done by the physiotherapist and other by the occupational therapist. The physio tests look at mainly the lower limbs and the occupational therapy tests assess the upper limbs.

Physiotherapy Assessment

The first thing we look at is physical strength with grading from 5, normal; 4, a little weak; 3, just being able to move against gravity; 2, can't move against gravity; 1, a flicker of movement; 0, no movement.

Then there is assessing overall function. The legs function in two ways, one is to keep us upright and the other is to move around. Some patients have lost feeling in their feet and rely more on their eyes and ears to tell them whether they are upright. Our tests involve checks on the ability to stand still with eyes open and with eyes closed, to measure basic balance. Another test is to check how many times you can step up and down on a small platform in 30 seconds. This involves strength, balance and coordination.

There are various walking tests such as how long it takes to walk ten metres at walking pace. The Timed Up and Go Test, originally used in Parkinson's Disease, involves timing the getting out of a chair, walking a certain distance and returning. A six minute walk on a treadmill to measure the distance travelled was also used to start with.

The Ambulation Index assesses walking ability with a questionnaire, scoring from 0 to 5. Other questionnaires can also be used but we now rely mainly on the walking tests

Occupational Therapy Assessment

Occupational Therapists are good at assessing and helping people with overall function. They do some strength measurement, such as ability to squeeze, or to spread the fingers. Then there is the test for coordination using the Purdue Pegboard ? the number of pegs you can place in the board with

each (or both) hand in 30 seconds is counted. A modification is an assembly test placing four objects in order over a pin, using both hands.

So we have two sets of therapists who are assessing function, getting some idea of disability from questionnaires and doing strength measurements, for assessing patients with neuropathy, predominately with CIDP.

Overall Strategy

Our overall strategy is to use this test approach for patients with chronic neuropathy to determine any change, especially in those patients requiring continuing treatment. We get a baseline measurement and then after some interval (we choose two weeks) we repeat the tests. Most patients will improve after a few days or a week and achieve a peak response after two weeks. We compare the two and then repeat over several cycles to see if the changes are reproducible and/or changing over time.

The results come to me and I put together a report which goes back to the treating doctor. The doctor gets an enormous set of figures with a summary statement about his patient. If the figures reveal the patient is much better, there is good reason to going with the Intragam. This is the way it works in most of our cases.

Occasionally we get the other circumstance. The patient has had the Intragam a number of times and there has been at best only a little improvement. In this case it is concluded Intragam has not been effective. The treating doctor then has to consider whether it is worthwhile continuing with the Intragam.

Some Results

I compared the results of fifty patients being treated with Intragam. The best success was with 16 CIDP patients where 8 showed positive improvement, 6 were marginal and 2 were negative. One of four MMN and one of four Myasthenia patients showed positive improvement whilst there was no positive improvement in 15 Other Neuropathy patients, 8 LNN Syndrome patients and 3 Myositis patients. One weakness of these results is that the dosage of Intragam can vary. Notwithstanding such uncertainty the ARCBS may look more favourably on our requests for Intragam because of these objective results of the Monash Test Battery. Other hospitals are using or developing similar tests.

Questions & Answers

Q. My neurologist diagnosed me with Progressive CIDP. He found Intragam was the best treatment to stop it progressing. Would stopping of Progress be sufficient justification for continuing treatment?

A. In order to show Progress reliably you would need measurements beforehand. If these showed you were getting worse steadily and then the Intragam stopped the Progress then the treatment would be justified. The main difficulty is that most patients are reluctant to have a period of several months of no treatment just to show they are getting worse. Keeping a patient at a stable level is just as important as preventing deterioration.

Q. When my Intragam was stopped due to a recent DHS decision, my condition deteriorated. Does your Test Battery include any such stoppage?

A. No. What we do at time, if the patient seems stable, is extend the period, say from 4 weeks to 6 weeks, to see if there is any deterioration. If so then the initial period is restored.

Molly Guntarik-Campbell 15-3-51 ? 26-5-04

Molly passed away peacefully in the Bendigo Base Hospital surrounded by her family. She worked hard to combat her CIDP and remained courageous and optimistic during her five year battle. Molly was an enthusiastic supporter of The IN Group, serving on its Committee and attending many functions. She and her family felt very supported by The IN Group ? a wonderful source of information and friendship.

Steve Campbell

Dear Steve,

The IN Group?s profound sympathy for your and family?s loss of a great person. We could not have written a better tribute to her wonderful support of The Group. (See also tribute on back of wrapper.)

James Gerrand, Director.

"THE AGE" 17/06/04

(Thanks, KYLIE, for this great publicity)

A Sunbury Circle

Good afternoon James,

I had GBS 7 years ago last May and I would like to become a supporting member of The IN Group. (She has joined.) JAN LANE of Sunbury, another GBS person, who is now a very good friend of mine (I had first met JAN when she came home from hospital as I was then a "recovering GBS" person) gave me your email address. Could you please send me some information.

Many thanks, CAROLE SCOWN, Sunbury.

(Sent GBS booklet, IN brochure, and newsletter.)

Dear James,

Here?s my membership renewal and donation for 2004. I love receiving the newsletters. Sorry I can?t get to any of the meetings but distance is quite a problem for me. Since I contacted you 12 months ago, myself, JAN LANE from Sunbury and another lady from Sunbury, CAROLE, get together every 4 months for coffee and catch-up. It is fantastic to be able to talk to others who have had GBS.

Take good care, ELSIE McCARTIN.

Then there are our Country Cousins (USA)

Mr Gerrand,

I normally look forward with great anticipation to the arrival of your "Information" newsletter and I immediately read it through completely.

But today I was saddened as I read of the passing of my wonderful friend VILMA CLARKE. I have enjoyed our "long distance relationship" over these past years Her cheerful attitude always gave me encouragement during times of despair as we all try to deal with this medical problem we have.

Hoyt Slaton, Alabama USA.

Dear James,

Thank you for responding so quickly (Thanks to the Internet! J.). I did not receive any treatment for my GBS. I went to the emergency room after a week of onset and they told me I must have a ruptured disc and sene me home with muscle relaxors which I didn?t take. I called every neuro in town but they couldn?t see me for a month or so. I just kept on working which when I look back was crazy. I shuffled my steps because I couldn?t pick up my legs. I know I didn?t have as severe a case as others but I feel a great loss of ability to have a normal life. I have suffered from about three months of my GBS. When I did get a spinal puncture the GBS was confirmed but most of my symptoms had disappeared by then. I also had Bell?s Palsy after about 3 weeks after onset.

Catherine Nuccio, Florida USA.

Dear James Gerrand,

Thank you so much for getting back so soon (Again the Internet. J.). My grandmother (in-law) was diagnosed with CIDP about a year ago. She lives in Florida and we are extremely far from her. I know she hasn?t received much of anything. She is to see a doctor soon. She has really no upper body strength. I just got involved with this because her "family" doesn?t seem to help. I have never heard of this condition so please bear with me.

Loretta Morrone, New Jersey USA.

Dear James,

Thank you so much for responding. Do you know anything on how to deal with tingling in the hands? I have been having a lot of problems writing and driving. It also wakes me up at night. The CIDP is now affecting my arms and hands. The first time was my legs. I went back on the IVIG treatments in April. They did seem to work. Now I am not sure why? My problem is I work and its difficult to get to the doctors. But I am starting to to think now that my health comes first. Doesn?t seem to be that much out there on CIDP. Thank you again for your help.

Kelly Schoonmaker, New York USA.

Reply

Dear Kelly,

Tingling in the hands can be part of the CIDP disorder. I occasionally get it but my fortnightly IVIG (24 grams) seems to keep it away.

I am posting you a CIDP booklet published by the GBS Support Group (of the UK), plus The IN Group brochure (containing membership application form) and latest newsletter "Information".

James Gerrand, Director.

IVIG Working Group

My name is John Burke, I suffer from CIDP and I am treated with Intragam at Monash Medical Centre.

I introduced myself in the last newsletter and advised you that I had been invited to participate as one of two "Patient Representatives" on an IVIG Working Group convened by the Australian Red Cross Blood Service (ARCBS). The other participants are representatives from the Victorian Government Department of Human Services (DHS) and doctors from a number of disciplines including Neurology.

The biggest problem we are facing regarding an adequate supply of Intragam is the level of Government funding for the ARCBS to collect blood plasma.

While the Victorian Government's budget for this financial year 04/05 still has not been publicly announced I understand there will be an increase in supply of IVIG over the usage of last year. However as ARCBS have advised that even prior to the March crisis they have only been able to supply approximately 75% of the IVIG that doctors have ordered, the proposed increase in IVIG will not even make up the current shortfall and has no allowance for any increase in demand.

The current status is that the ARCBS have advised that it is now "Pre-crisis business as normal". If you are not getting the IVIG quantity that you were prior to March this year you must ensure that you talk with your infusion centre nurse or Doctor.

I will continue to participate on the IVIG Working Group and report back through The IN Group newsletter and other avenues.

As an initiative to facilitate better communication within the IN Group I am compiling a list of email addresses. If you would like to add your address to the list please email me at:

jburke@contracts.com.au

If anybody would like to speak with me on any issue I can be contacted as follows:

John Burke

wk: 9885.2899

a/h: 9885.2377

mob: 0417 885 747

Your IN Group Committee

The following were elected as your Committee for 12004/2005 at Annual General Meeting of The IN Group, held 11/08/04 at the Balwyn Library Meeting Room.

Director: **JAMES GERRAND**

Deputy-Director: **MARGARET LAWRENCE**

Secretary: **ROSEMARY McQUALISTER**

Treasurer: **BRONWYN CLARKE**

Committee: **JOHN BURKE, PETER MALCOLM, BARBARA RIVETT**

There is a vacancy on the Committee. So we would ask any IN Group member who would like to assist to come to our next quarterly Committee Meeting, to be held on Wednesday 20th October at 7.30pm at the home of Betty and James Gerrand, 138B Princess Street KEW 3101. As well as contributing, you can see whether you would like to be considered to be co-opted to fill the current Committee vacancy.

If you decide to attend RSVP 9853 6443 by 4/10/04.

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