Review of The IN Group Epidemiology Study - GBS and CIDP

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*From the addresses by **Dr Malcolm Sim**, Senior Lecturer, Dept of Social & Preventive Medicine, Caulfield General Medical Centre, and*

*by **Dr Bruce Day**, Consultant Neurologist to The IN Group, to the August meeting of The IN Group, held 8/8/95 at 4 Alandale Avenue, Balwyn. JHG*

Dr MALCOLM SIM

A view of epidemiology

My background is that of a medical graduate with a PhD in epidemiology. My interest is primarily chemical exposures and their effects.

The classical definition is the study of the distribution and determinants of diseases in human populations. We are interested in the patterns of disease. Is it geographical, varying from country to country, or with latitude? Does in vary in time, are their peak periods, are there more now than before? Does it vary between groups of people?

As well as patterns we are interested in what factors may lead to disease, what are the causes, what are the risk factors? Is it exposure to various things, is it genetic? Could it be due to taking medications or to viral illnesses?

A whole science has been built up to design various types of epidemiology studies that can look at different diseases.

Looking at the study done by your group I am not sure what criteria was used for the diagnosis of the GBS or CIDP illness. For some diseases, for example asthma, it is difficult to get a strict diagnosis.

***Dr Bruce Day**: For GBS the more severe the case the more likely the diagnosis is correct. We are not so sure about the mild cases. The support group tends to select the severe cases so I think the GBS diagnoses can be relied on. The situation with CIDP is more confused. If the standard diagnosis criteria are used in a study we know that such a study will automatically exclude some CIDPs because of the endeavour to make sure that conditions that are not CIDP are excluded, ie for the sake of certainty atypical cases are excluded.*

Another important factor in epidemiology is the need for a control group or comparison group. I noticed one finding in the study that found that increased exercise had been reported by many as a common factor. Whilst this is an interesting finding, unless we can compare it with a similar group that has not the disease, it is hard to accept as being a factor.

Dr BRUCE DAY

The Epidemiology Study

This was intended basically as a pilot study to help determine what should be looked at in a more intensive and controlled study. Getting controls would be another issue. Spouses could be considered but this might introduce a bias in such factors as exercise, diet or exposure to viruses, etc.

Question 9 of the study asked whether 21 illnesses may or may not be associated with a predisposition with GBS or CIDP. Most were recognised auto-immune disorders that had a potentially similar pathogenesis. We did not draw much evidence of any connection. Of course the numbers questioned were quite small.

To do the study more conclusively one would like to recruit people at the

time of diagnosis but as inflammatory neuropathies are quite uncommon it would take a few years to recruit significant numbers. Recruitment as soon as possible after diagnosis leads to fewer errors in the recall of potential precipitating factors.

Reviewing the published studies to date show that our understanding of GBS is changing at a relatively rapid rate. Many of the past studies have found no seasonal variation except in the Third World where some increase is seen in summer. The latter has generally been disregarded because of the uncertainty of the diagnosis. Now we know that the patients (mostly children) did have GBS but of an unusual and, until recently, unrecognised type. This seasonal variation (found most strikingly in Northern China) seems to be part related to a campylobacter infection. Some GBS patients in more developed countries have also had preceding campylobacter infection and this observation has also been made here in Melbourne by doctors working at Fairfield Hospital.

Campylobacter gastro-enteritis is now a well-known precipitant of GBS. Other infections such as chest infection with mycoplasma pneumonia may also cause GBS although it more commonly causes transverse myelitis or cerebellar ataxia. On the whole however infections of this sort have a low propensity to provoke GBS.

Viral infection on the other hand has been quite strongly associated with subsequent GBS, the viruses CMV and EBV being two most commonly implicated. The AIDS virus can also produce a GBS-like syndrome but there are some recognised differences especially in the spinal fluid where there tend to be high numbers of white cells in HIV associated cases.

In areas where HIV is common up to 10% of GBS patients will have the HIV virus.

There are two vaccines that are well known to produce GBS. Both are now rarely used in Australia. One is the smallpox vaccine and this used to produce GBS in people who had been re-vaccinated. The other is the rabies vaccine that used to be prepared from adult animals but now that it is prepared from egg yolks and suckling mice there is a much lower incidence of GBS.

There was an epidemic in the USA in 1976 when some 4 million people were vaccinated with the swine flu vaccine followed by a sudden and alarming increase in GBS cases. This was perplexing because the vaccine had already been used extensively in the military without serious complications. It was not clear whether this was some form of statistical artefact or a real complication. The controversy rages to this day as to whether this vaccine really was associated with the GBS increase. At most the vaccine probably doubled the rate of GBS.

Tetanus toxoid boosters have rarely been associated with lapses of CIDP.

There are other agents that are associated with GBS. There is an association with surgery - a mechanism which is not understood but it is thought surgery may interfere with nerve sheaths thus

triggering some sort of immune process. There is an association with pregnancy and there have been interesting cases where women have had GBS relapsing after each pregnancy.

When it comes to medications there is some association with the use of gold in rheumatoid arthritis, and with the use of an anti-depressant known as Zimelidine. The agent has since been withdrawn from the market.

One surprise from the study was the possible relationship to exercise. We graded exercise into several levels. RARE is for example where one chops wood once a year. INFREQUENT regular would be one who plays football once a month . FREQUENT regular is one who plays sport competitively once a week. In our study patients clustered heavily towards the frequent regular exercise prior to the onset of both GBS and CIDP. My perception is that in the age groups of the respondents this level of activity is unusual. Clearly good controls are needed to validate this finding.

The other finding of interest was the number of CIDP sufferers who ascribed stress as a possible factor relevant to their illness. It raises the question as to what role stress has in prompting auto immune disorders. Much research is being done presently into the relationship of stress to physical illness. This is a very complex area and few clues have emerged. One problem is defining stress and another is differentiating cause and effect.

As regards future research and the possibility of obtaining grants for such research, there is certainly much work to be done in inflammatory neuropathies. Because of its complexity the magnitude of funding for what is after all a relatively small number of cases is unlikely to be available in Australia. Most of the leading edge research is probably not going to be done here. The resources allocated to medical research in Australia do not compare to those of US, for example even on a per capita basis. In many respects Australian medical research funding levels are so low that there is little encouragement for accomplished researchers to continue and for junior researchers to enter the field. This comes at a time of an unprecedented growth internationally in biological science based knowledge with the expectation that industries based on this knowledge will be the major growth industries of the 21st century.

One of the great benefits that support groups such as The IN Group can bring is to raise the level of community awareness regarding the need for well conducted research to unravel the mysteries in these disorders and hopefully lead to better treatments and outcomes.

Support - The Name of our Game

Dear James,

I visited Eleanor Myring last Thursday 27/7 at Cedar Court Rehab. She seemed pleased to see me to have a chat about the GBS which she has had for two months. At this time she is learning to use her legs up and down the race, is quite proud of it. It's the start of the homeward journey.

On leaving, Eleanor was a lot bri- ghter for being able to discuss certain happenings of the GBS.

JESSIE BRAGG

Surrey Hills

and a thank you

Dear James,

I am writing to thank you personally and could you also pass on our thanks to Jessie Bragg as I haven't got her address, for visiting my mother so promptly after my call to you.

My mother has been suffering from GBS for ten weeks now. Fortunately she is now on her way to recovery and is currently undergoing intensive rehabilitation at Cedar Court.

This Syndrome is certainly a very debilitating illness and it was great comfort to Mum and her family to hear of the work and support that you as Director and the members of The IN Group offer other sufferers.

At the moment Mum is unable to write legibly but she would like to express her thanks also to Jessie for her very cheerful and encouraging visit.

We are hoping that before too long Mum will be able to return to her property at Greta West and continue her volunteer work in the local community.

I would like to wish all IN Group members continued good health and best wishes for the future.

JAN MARTIN

Ferntree Gully

Help from John Stanley

Dear James Gerrand,

I have received much information on GBS and support groups of NSW & Vic from John Stanley, Devonport TAS after reading his story in "New Idea". I have joined the NSW GBS Assocn. and perhaps I could join Vic too? (Yes, she has. J)

I entered hospital on 3/12/94 and was diagnosed GBS that day and immediately commenced treatment - the

early diagnosis and swift action enabled me to spend only two weeks in hospital and I am now greatly recovered (fatigue being the most inconvenient residual).

During the initial days and recovery time it may have overcome my frustration if I had information that I have now received, that the treatment provided would almost certainly work and that recuperation would take some time. No one then could really inform me other than that I HAD it.

I know I was very fortunate in that others have been in much worse condition than I experienced and I have been able to recover in minimal time but it was still quite a frightening time for me and my family.

My friends and family were so very supportive (as much as they could be - none of us knowing what we would be dealing with).

ENID BROWN

Chigwell,TAS

Dear James,

Feel very guilty in renewing my sub as I have not done anything for The IN Group this year. I prefer to do rather than be done.

Your INformation newsletters are very welcome and informative as they are meant to be. I am amazed at the progress of identification and treatment of GBS to which I relate. What wonderful change in 20 years and what dedicated people there must be helping those affected.

If posters are sent to our area I would suggest Base Hospitals at Warnambool and Ballarat plus St John of God Hospitals at both those places.

I know that country living is healthy but I cannot believe that I have not heard from any patients throughout this area for years. If there hasn't been a case in that time I am more than pleased.

May I apologise for non-attendance at the Annual Meeting, I expect to be crossing NSW that day en route to an annual hydrotherapy plus R&R at Noosa. I wish every one good luck for the year plus many thanks to you and Betty and the team for the continuing work on behalf of IN.

GREG GILLESPIE

Peterborough

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