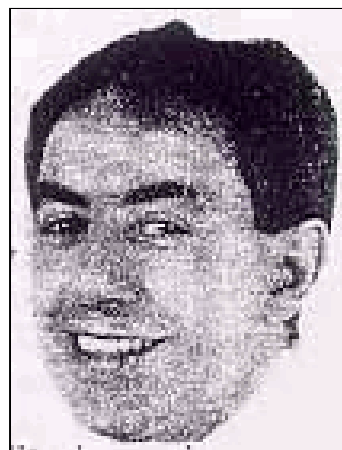


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Update on GBS and CIDP Research

Newsletter No.19 - June 1997

From the address by Dr ANDREW J KORNBERG, Neuromuscular Laboratory, Royal Children's Hospital, Melbourne to the quarterly meeting of The IN Group held 14/5/97, Balwyn Library Meeting Room, 336 Whitehorse Rd. (This report is based on notes supplied by Dr Kornberg rather than on a recording of the address. Unfortunately the recorder was not on. JHG)



Research plays an important part in the treatment of patients with neuropathies. It wasn't too long ago that a person may have gone to their doctor, diagnosed with a neuropathy and told that no treatments existed. However, both clinical and laboratory research have provided considerable information over the last few years that have made an important difference to management of patients with neuropathies.

A significant step has been the use of different techniques to diagnose and classify neuropathies. This sort of classification has provided information to doctors suggesting that many of these disorders are immune-mediated, that is, the person's own immune system fights their own nerves. It has been known for many years that immune disorders could be treated with medications. With this knowledge, the first steps towards providing beneficial treatments for patients with these neuropathic disorders began. More specific treatments have become available based on research into how these disorders are caused.

Treatment has allowed people afflicted with these problems to return to normal and independent lives, and the hope is that more specific treatments with less side effects will become available.

Clinical research has evaluated the benefits of different treatments. Analysing whether one form of treatment is better than another is important as this will allow patients to be given the most effective treatment available. For example, recent studies have shown plasma exchange to be equally effective as intravenous gammaglobulin in GBS, and that there is no increased benefit in using both treatments in any one patient. The importance of this cannot be understated. Clinicians can choose an effective treatment for a patient and not resort to extra therapies that do not add any benefit. Indeed, not adding extra treatments may decrease the risk of added side effects, and also keep costs in our current economic climates to reasonable levels.

Basic or laboratory research is important in that it may allow more specific tests to be devised, for diagnosis and treatment follow-up. Probably, more importantly, laboratory research may be able to unravel how the condition was caused in the first place. Understanding how a disorder is caused may allow more specific and safer treatments to be devised.

Diagnosis of Immune-Mediated Neuropathies

The diagnosis of an immune-mediated neuropathy is based on a number of different patterns clinically or on investigation.

1. Clinical Patterns

Typical clinical symptoms and signs may help diagnose some immune-mediated neuropathies.

2. Tissue Involvement

The type of tissue involvement is based on the investigations your doctor may perform. These investigations may include nerve conduction studies (electrical tests), nerve biopsy or antibody testing of your blood.

Inflammatory Neuropathies

A list of the various immune-mediated neuropathies follows. The common thread is that they may be treatable whereas many other neuropathies do not have any treatments available.

- Guillain-Bare syndrome (GBS)
- Chronic inflammatory demyelinating neuropathy (CIDP)
- Multifocal motor neuropathy (MMN)
- Myelin associated glycoprotein (MAG) neuropathy
- Others, including vasculitis, paraneoplastic syndromes

Research in Inflammatory Neuropathies

Present main areas are:

- What causes the disease?
- Better Tests?
- Better Treatments?

Molecular Mimicry

This occurs when an infectious agent shares epitopes (something an antibody binds to, other than antigen) with host antigens. The ensuing immune response (B or sensitised T cell) will be against not only the infectious agent but also against the cross-reacting epitopes of the host autoantigen.

Antigen-specific T cell activation occurs with tissue injury.

The Campylobacter Story

Campylobacter jejuni is an organism that causes gastroenteritis. It has been implicated in GBS in about 30% of cases. It is an organism that shows features of molecular mimicry. Some of the evidence for molecular mimicry includes the common association of the organism with GBS, the association with GBS in China which may be transmitted by chickens, and the structure of the organism which may give clues as to why it is associated with GBS.

Recent Advances

Some of the recent advances in the laboratory revolves around the measurement of antibodies in blood. This may help classify a neuropathy and thus provide information as to whether the neuropathy is treatable, and if it is treatable, which treatments are best.

It has been found that:

- Specific IgG GM1 antibodies are associated with acute or chronic axonal motor neuropathies.

- Specific GQ1b antibodies stain the cerebellar molecular layer.
- Subfractions of sulfatide predict specific neuropathic syndromes.
- Patterns of reactivity to GM1, HH3 and NP-9 are specific in MMN and LMN syndromes.

Anti-GM1 antibodies

These are commonly found in:

- Multifocal motor neuropathy (IgM).
- Lower motor neuron syndromes (IgM + IgG).
- Acute axonal motor neuropathy (IgG).

IgG Antibodies to Selective GM1 Ganglioside

This pattern of reactivity predicts:

- Acute axonal motor neuropathy.
- Chronic asymmetric lower motor neuron syndromes.
- "Chinese paralysis syndrome".
- May have prognostic significance.
- May give a clue to the pathogenesis of these disorders.

IgG to GQ1b

This is another antibody that is associated with a particular neuropathy. It is very strongly linked to Miller Fisher syndrome and variants (observed in all patients reported), seen in Bickerstaff encephalitis.

- There is some evidence of pathogenicity.
- Titres (quantity by titration) high early and low during recovery.
- Treatment with reduction in titre associated with clinical response.
- Monoclonal anti-GQ1b immunostain some tissues affected.
- Serum from patients can block neurotransmitter release.
- Botulism toxin binds to GQ1b receptor.

Immune Mediated Neuropathies: Treatment

- The identification of immune-mediated neuropathies is important as these disorders often respond to treatment.
- Patterns of binding of serum M-proteins and autoantibodies correlate with, and may be diagnostic markers for, specific polyneuropathy (PN) syndromes.
- There is evidence that some of these antibodies may play a pathogenic role in PN syndromes.
- Identification of specific immune PN syndromes provides guidance regarding immunosuppressive regimens that may be effective treatments.

CIDP - Treatment

- Prednisone is a standard treatment for CIDP.
- Plasma exchange is useful.
- IVIG treatment may produce short-term improvement of strength in 25%-60% of CIDP patients.
- Cyclosporin A may also be useful.
- Other treatments may become available

Guillain-Bare syndrome

- Supportive management is still the mainstay of treatment of GBS.
 - Technical difficulties in the use of plasmapheresis make IVIG an attractive alternative.
 - Criteria for treatment as for plasmapheresis.
 - IVIG dose is 1-2 gm/kg patient weight/day over 2 days.
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Inaugural Meeting of the Council of GBS/CIDP Associations of Australia

On Sunday 27th April the inaugural meeting of the Council was held at Melbourne with support from the **Neurological Resource centre of South Australia**, the **GBS Support Group of Tasmania** and the **Inflammatory Neuropathy Support Group of Victoria (The IN Group)**.

The primary purpose of the Council is to establish and promote agreed policies to promote national support for GBS and CIDP sufferers.

BARBARA BURZAK-STEFANOWSKI (IN Group of VIC) was elected President, **HEATHER TRENORDEN** (NRC of SA) Vice-President and **MELVA BEHR** (IN Group of Vic) Secretary/Treasurer.

The next meeting of the Council will be held on Sunday 3rd August in Melbourne when it is expected a representative from the **GBS Association of NSW** will attend.

A major help to the formation of the Council was its sponsorship by **CSL Ltd** with a generous donation of \$500. **CATHRYN HOPE**, CSL's Immunotherapy Product Manager, Bioplasma, expressed CSL's support in the following:

"The establishment of a National council to encompass the various support groups within Australia is an excellent step forward ..."

Thank you once again, **CSL**.

It was also pleasing to receive the following support from our Patron **JOHN POLLARD**, Professor of Clinical Neuroscience, The University of Sydney:

"I do support your move in this direction and think it most appropriate that there be a national group for all the reasons that you propose. I would support you in this move in any way I can."

Those attending the inaugural meeting were:

Delegates: James Gerrand, Barbara Stefanowski, Vilma Clarke (The IN Group of Vic Inc); Heather Trenorden (NRC of SA Inc); Betty Gerrand (proxy delegate GBS Support Group of Tas).

Observers: Werner Fiedler (CSL); Keith Colwill, Joe Behr (The IN Group).

A pleasing meeting with NSW Association

Betty and I were pleased to accept an invitation to have afternoon tea with the committee of the GBS Association of NSW on Saturday afternoon 26th May. We were in Sydney that week to attend my sister's 90th birthday celebration. It was good to put faces to names and to discuss and be informed about our respective support activities and problems.

I was particularly pleased to meet President **DUNCAN MACPHERSON** and Secretary **JAN AYRES**, and to be informed by Duncan that he hopes to come to Melbourne to attend the next meeting of the national Council on Sunday 30th August.

JAMES GERRAND, Director

A successful Linen & Basket Party

Secretary **VILMA CLARKE**, demonstrated a large range of linen and baskets to a small but enthusiastic group who attended the party at the home of committee member **MELVA** and husband **JOE BEHR** at their Sunbury home.

\$175 was raised for The IN Group which will pay for a **Doona Cover, Queen Size**, to be raffled at a later meeting of the Group. Thank you, **VILMA** for organising the party, and **MELVA** and **JOE** for your hospitality, including a great session in your spa.

Attendance at Chronic Illness Alliance

VILMA CLARKE and **MELVA BEHR** were our two representatives at the National Conference of the Chronic Illness Alliance, held 28/4/97 at 330 St Kilda Rd Melbourne.

Main topics considered were:

- The Government response to the needs of people with chronic illness.
 - The social changes required to improve the lives of people with chronic illness.
 - Models of best care suited to people with chronic illness.
 - Reform of the Pharmaceutical Benefits Scheme.
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Notice of Annual General Meeting

The AGM of The IN Group will be held commencing 7.30pm on Wednesday 13th August at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn, immediately before the address by Dr Tony Moore on "Caring for the GBS/CIDP Patient" (see details on wrapper).

Members who would be interested in helping The IN Group as an office bearer (President, Vice-President, Treasurer, Secretary) or committee member, are invited to nominate on the form supplied on the back of the wrapper.

Winter Luncheon - Sunday 29th June

Members, family and friends: here is the opportunity for a pleasant social get together over soup etc, Balwyn Meeting Room, just \$5. For details see flyer inclosed.

GBS/CIDP Awareness Day - 1st May

Following the lead of the USA support group, GBS Foundation International, the Public Relations Officer, **MELVA BEHR** of The In Group spread the message to the Victorian media.

JIM SADLER rang to report he had read about the Awareness Day in his local Malvern press (sent in by **CLAIRE BROOKS**). He had suffered from GBS some years ago but now he knew of The IN Group he would join and would like to assist, one very welcome result.

Otherwise the response of the metropolitan newspapers, radio and TV stations, was disappointing (I did receive a call from a reporter from the Melbourne "Herald Sun" who arranged to interview me whilst undergoing my fortnightly Intragam drip at the Alfred Hospital but she didn't show up).

However there were two great stories in the country press, as shown on this and the next page - [JUNE CATHCART's story](#) was featured in the "Stawell Times-News", [MARGARET BREW's story](#) in the "Pakenham Gazette".

It can be expected that an even better media response and one Australian wide, will be achieved next year through action by the new **Council for GBS/CIDP Support Groups of Australia**.

Support is the Name of our Game

Clusters

Secretary **VILMA CLARKE** from her base at Wangaratta has been keeping touch with her North-Eastern Cluster with members **LURLINE BUTLER** and **GLADYS DEMPSTER**(Lavington NSW), **TRICIA FOLVIG**, **JILL GRIMMOND** and **ALMA LINE** (Wodonga), and **JOHN WARD** (Beechworth).

Committee member **MELVA BEHR** is endeavouring to develop a cluster for the Sunbury/Footscray area.

Whilst not yet with a cluster, **GREG GILLESPIE** (Peterborough) does a sterling job in looking after the South-Western area. His latest report includes;

*"I have been to the Warnambool Base Hospital to see Barrie Steel a few times, he is bright and optimistic, let us hope he remains so. There is no question he has a long way to go but he is showing a little progress; he is breathing without support during the day but requires a little help at night. He is still unable to talk so communication is difficult, we get by but it is frustrating for the lad. Boredom is a problem as his friends have to travel some distance to fit in with their own occupations. He is improving in some shoulder movement but little in arms and legs." (Barrie with his wife has a dairy farm and two sons about 5 and 7 and twin daughters just a few months old. He was badly paralysed by GBS and spent some months in the Royal Melbourne Intensive Care Unit where he was visited by member **Brian Luscombe** and myself. JHG).*

"Had a classic example of communications problems last week: telephone call from the Hospital Care office wanting information on GBS; nobody had heard of it before. After my visit I found your poster on the Nurses Notice Board but it had gone unnoticed. To try and overcome this glitch may I suggest that The IN Group Newsletter mailing list include the Community Care Department, Warnambool Base Hospital, Royal Street, Warnambool 3280." (Have done and thanks, Greg.)

Appreciation from Geelong

Hello James,

"...I am currently receiving plasma exchange from the Apheresis unit at the Geelong Hospital by a beautiful nursing sister - Susanne Burt. She remembers you fondly and would appreciate receiving the Newsletter. I would like to pay the \$15 for her membership ..."

I would also like to attend "An Update on GBS & Cidp Research" with Dr Kornberg on 14/5. I will try to bring someone with me.

*Many thanks, **BARBARA HYATT***

A Trying Time with Recurrent GBS

BROOKE TAYLOR, a young married woman, has had a further recurrence of her GBS. Her mother **JAN LITCHFIELD** reports:

Dear James,

Many thanks ... for your offer to visit. Brooke would very much appreciate any visit but is now at home (in the country) once again. She had a triple dose of Intragam and now, a week later, is probably stronger than she has been for quite some time. We are hopeful that this will last and it is just a matter of the cyclosporin starting to take effect. Of course she has a long way to go, and she is still unable to do such things as dressing herself, bathing herself etc. She does feel much better about the fact that she can feed herself!! I guess that once she does gain enough strength to actually get some exercise, she will be able to slowly build on it to enable her to perform more tasks than she has been able to for a long time.

She is, of course, becoming quite exasperated and frustrated at times but mostly manages to put on a brave face.

*Regards, **JAN LITCHFIELD***

At the Royal Talbot Rehabilitation Centre

When I visited **BOB LINTON** in May at the Centre he told me that his neurologist regarded his case as an enigma. Bob's condition has been deteriorating and he was in a wheelchair. His wife **UNA** has now told me that Bob has now been examined by Dr Kornberg who has advised that his tests show Bob has not got CIDP but he needs to carry out further tests to try and determine just what is affecting Bob.

Una was full of praise for the Occupational Therapist and Social Worker from the Centre for making a visit to their home to advise how best Bob's needs could be met there.

Bob's trial is an unfortunate demonstration of the difficulty there is sometimes in determining a clear diagnosis for neuropathy cases.

At Royal Cedar Private Hospital

DOROTHY BRENNAN, who attends the Hospital each week for hydrotherapy, visited **DAVID ASHTON** there whilst he was recuperating from a mild stroke. I also saw him there and he seemed to be enjoying the care and attention of the nurses. David is now back home and his main problem is being told not to drive his car due to the unsteadiness in his balance. Best wishes, David, for

regaining your mobility.

At the Southport (QLD) Hospital

BETTY GERRAND received a long call from a Michelle Cox, mother-in-law of 19 year-old Sally who was in the Hospital Intensive Care Unit, paralysed with GBS. Michelle was wanting information about GBS so, to supplement Betty's advice, we sent her up the GBS booklet published by the US GBS Foundation International which The IN Group has reprinted.

Husband Garren Cox has now advised me that Sally has progressed to transfer to the Rehabilitation Unit and they are very pleased with the information we sent. Garren, as a fanatical Collingwood supporter, wearing their football jumper with N0.19 on the back, is looking forward to a letter from our member **GRAH-AM WRIGHT**, starring once again with Collingwood as their No.19.

Membership

The support The IN Group is able to provide is very dependent on our membership. It is pleasing to receive so many expressions of support, often accompanied by monetary donations.

The membership now totals 221 and includes 30 from overseas (19 USA, 3 UK, 3 NZ, Austria, Canada, Japan, Philippines, Slovakia) and 26 from interstate (9 NSW, 1 ACT, 4 Tas, 3 WA, 2 SA, 7 Qld).

Questionnaire

It is noticed from the Internet Home Page of the GBS Association of NSW that they have a very good questionnaire inviting members to provide a lot of detail about the history of their disorder.

This should be very helpful in providing support for a sufferer, particularly when endeavouring to support a sufferer with a member who has had a similar history. Presently we have mainly to rely on our memories.

So, hopefully, we plan to introduce something similar. This is a matter we also propose for discussion at the next meeting, 3/8/97, of the Council of GBS/ CIDP Support Groups of Australia as a start towards a national data base for member support.

A Rewarding Time on the Internet

Being on the Internet provides a very quick and easy means of communication between any two individuals situated anywhere in the world who are fortunate to have access on the Internet. For The IN Group this means being able to readily both give and receive help. Here are some recent examples.

Help at Ipswich, Suffolk, UK

LINDA BOOTH of Ipswich, Suffolk, UK, when diagnosed with CIDP found The In Group on the Internet and sought information on the disorder. I airmailed her the CIDP booklet published by the GBS Support Group of the UK which The IN Group has reprinted. She airmailed her thanks and her membership application and then asked if The In Group could help in locating somebody in the Ipswich area who could help her with some present difficulties. I emailed (sent on the Internet) a message to **ANDY LEITCH**, Editor of the UK Support Group magazine "Outreach" asking his help.

He replied forthwith that he had just received his Group's latest data base and yes, there was a gentleman with CIDP at Ipswich who should be able to help. Andy arranged for the two people to be in contact and the help was effected. So through the Internet within a couple of days the problem was solved.

"INformation" article republished in UK

I received a message from the above Andy Leitch, asking permission of The IN Group to republish the article "Illness as a Stress and How We Deal with It" based on the address by psychiatrist Dr David Lowenstern which had been published in our newsletter "INformation" of March 1996 and subsequently put on The IN Group Home Page (as we do now with each issue of "INformation"). I replied I would have to get Dr Lowenstern's OK. The latter agreed with delight for the article to be seen in the UK. Andy subsequently published the article in the UK support group magazine "Outreach" No.32 Spring'97 with kind acknowledgment to The IN Group.

In the same issue of "Outreach" it was pleasing to read in the News section another acknowledgment to The IN Group in assisting the translation of the UK CIDP booklet into Japanese by Takako Kanai. Takako whose husband suffers from CIDP contacted The IN Group for information. I sent her the CIDP booklet plus our brochure and recent newsletter. Takako subsequently asked if she could translate the booklet into Japanese. I replied she would have to ask that of the UK Support Group. This she did, got their OK, she translated and sent a copy to the UK. Andy Leitch kindly sent a photostated copy of the Japanese translation to The IN Group.

Many Inquiries for Info on CIDP

Whilst Betty and I were away in Syd-ney for a week in May celebrating my sister **HATTIE LAVER**'s 90th birthday, five people sought information via the Internet on CIDP - quite a peak number of inquiries. They were Mona Kunz on behalf of church friend Doug Richardson of Haughton, Louisiana USA; Linda Anderson of Andrews North Carolina USA; Jason White, on behalf of his wife, of the University of Tennessee College of Law USA; Joannanbob of Yucaipa, California USA; Barry Glen, on behalf of his brother-in-law, of Edmonton, Alberta Canada.

Double Blind Test Not On

I received a message from Thedogcat@aol.com

"My wife Susan is a RN (registered nurse) and has been preliminarily diagnosed with CIDP by a neurologist where we live. She has an appointment for additional testing at the University of Texas Southwestern Medical Center, where she will hopefully qualify to participate in a double-blind test that is underway on the effectiveness of immunoglobulin treatment.

She is not absolutely comfortable about participating since she is in much pain now, may (50/50) receive a placebo for 6 weeks before receiving the real thing. We are interested in the results of other CIDP patients who have had this treatment, and its cost. Also we are looking for more detailed info on CIDP. Any help will be appreciated."

I replied:

"Dear husband of Susan,

I must say I am surprised that the University is proposing a double blind test if there is a 50/50 chance of Susan not being given gammaglobulin treatment.

IVIG has been shown to be one of two top measures for treating CIDP, the other being

plasmapheresis. If Susan was my wife I would demand that she be given one of these two treatments at least.

...

James Gerrand, Director.

TOTAL SHAME

Barbara Beltz sent a message to The IN Group seeking info but miss-spelt "group" as "grope".

I replied pointing out the miss-spelling and received this reply, headed "**TOTAL SHAME**".

"OF ALL THE PEOPLE IN THE WORLD YOU ARE THE VERY LAST I WOULD WANT TO SEE MY GROPE POST. Yep, the very laaast person that I wanted to be on line but of course with my luck well!!!! Actually I am rather tickled. leave it to me to flub up good. And then you posted another message to me and even spellled past = apst and 78 or not I think I am in love with you. Truly I do thank you so much. A person sits and deals with all the scary details of this disease and starts taking themselves too serious. A good laugh is fine medication. I also want to thank you for all the good info that I and my daughter have gotten from your group (see I can spell it right).

I called my daughter from the Dr office and told her I didn't have MS and to look up GBS. By the time they put me in the hospital she had found you folks ... and several other sites downloaded and printed it up for me and brought it to the hospital. For a week in ICU I clung to those pages reading each word so it's only right to finally thank you. I guess your use to this but if you don't tell Betty on me I'll send you a big long distance kiss.

Peace, Barbara".

What can I say but thanks for the laugh, the thanks and the kiss, Barbara.

James Gerrand.

Last Updated: 15 Oct 2007 17:49