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# New AFOs (Ankle Foot Orthoses)

Newsletter No.39 - June 2002

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## How Reflexology may help

*From the address by MEGAN KNEEBONE, Orthotist, Orthopaedic Appliances Pty. Ltd., to The IN Group meeting, held Wednesday 8<sup>th</sup> May 2002 at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn.*



**STEPHEN COHEN** first paid tribute to the help he has obtained from Megan. Without her he couldn't walk. She has made his splints (ankle foot supports) for the past ten years. He was diagnosed with peripheral neuropathy 17 years ago. A particular reason for his recommendation for Megan to talk to the Group was her company's new AFO which has improved his walking ability and gait.

**MEGAN** explained that an orthotist makes and fits all types of orthotics ? braces to help anywhere on the body, from the feet up to the neck ? such as ankle, knee, neck braces. A jocular description is "spare parts for humans". Megan is a Bachelor of Applied Science in Prosthetics and Orthotics at Latrobe University. Prosthetics are artificial limbs. Latrobe University is the only place in Australia and New Zealand where one can train in this profession. About 20 graduate each year. Her company services Monash University for their orthotics needs. They have a large paediatric department so she obtained much experience in providing splints for children.

An Ankle Foot Orthosis is any type of brace that controls some of the ankle motion, unwanted usually. For example your ankle is letting your foot drop. Historically the design of AFOs has been dictated by the available material. When first produced metal was the only suitable material. Then plastic became available resulting in lighter AFOs, a great innovation. It provided contact with the leg, giving much better control, which was not feasible with metal.

However metal may still be applicable when you have some fluctuation in volume in the limb or the person is ill or frail. With both plastic and metal AFOs there are many different designs and componentry, depending on the individual need and aim. This is where the orthotist is there to prescribe and design what is needed.

In the last 2/3 years a Scandinavian company has designed and produced an energy storing foot for amputees. This was found better than the normal artificial foot; it allowed them to have a longer and faster stride and to stand or ambulate for a longer time. The company then applied this approach to a design of AFO which they called a "Toe-Off". The material used is a combination of glass, carbon and tefla fibres. This combination in various areas provides elasticity with good strength. The Toe-

Off works through having some flexibility in the foot section so as you are walking from heel to toe it is building up the energy to give you a push off. A plastic AFO has no such resilience.

*Comment from user Stephen Cohen.* Wearing the Toe-Off does feel as though you have a spring in your step, it does help you move forward.

Q. How long has it been available?

A. It has been available in Australia for about 2 years; we have been using it for the past 18 months. It has some disadvantages. If you have a lot of instability, side to side, it does not control that. There is also a problem that the fibres of the Toe-Off can delaminate with usage. Another problem due to its high technology is the cost (about \$700 each), being twice the price of a plastic AFO (about \$300 each). It is covered under the government PADP but there is a limit of \$1,200 for any orthoses. PADP will question why you need such an expensive brace. Some patients use private health insurance to cover the difference.

Q. When a patient is treated in hospital, is that paid out of Medicare?

A. I can only speak in regard to Monash Hospital. They have a system if the patient is an In patient they will cover the cost. Most of the children are In patients under the public health system. I believe most public hospitals follow this approach.

Q. Is it possible to try out such a novel device?

A. It really isn't. Although the Toe-Off is off the shelf, it needs some adjusting and correct fitting. You need to consider the heel height of the patient's shoe as to how much pitch they are putting on the splint. It is not something you can just quickly put in the shoe and the patient walks away. If you came to see me to see if Toe-Off would make a difference I would put one in to your shoe just as it is say for the 20/30 minute consultation and get you to walk around to get an idea as to how it feels.

*Comment.* I got CIDP some 10 years ago and have been treated at the Alfred Hospital. Initially they pro-uced an orthotic for my "foot-drop" but I found it was quite big and clumsy. The Alfred then provided me with a plastic set which I found helpful except that it tended to graze my calves. Then my "foot-drop" got a bit better so that I could get along without orthoses. However I would be interested in trying the Toe-Off.

*Reply.* In developing the Toe-Off they have successfully prevented the rubbing which you do get with the plastic AFOs.

Q. Can you drive a car wearing the orthotic?

A. Yes. It allows the foot to go down but you have to use your knee more. This is the same for all AFOs as they limit the ankle movement.

The company has yet to make an extra large Toe-Off because such a size is not strong enough. The design is still in its infancy.

*Comment from Stephen Cohen.* From my experience wearing the plastic AFOs for some 15 years is that they are more pliable and Megan used to change their shape by melting to suit the shape of the ankle/foot/calf and put padding in. It is not well known that an orthotist can do a number of things to modify an AFO to suit. As one example, the only sport I could do was skiing and I was devastated when my "foot-drop" got worse. Another orthotist built some custom AFOs for my ski boots. That helped.

Some patients don't require a large brace so orthotists provide smaller orthotics. Various materials can be used from soft to hard.

Q. How does AOPL go about looking at new developments and deciding whether to bring them into Australia?

A. There are many conferences around the world. One of AOPL staff members usually attends such conferences where new developments are shown. It must be said that many are just reinventing the wheel.

Q. to Stephen. How do you walk without an AFO?

A. I can walk but with difficulty. I don't walk outside the house. It would be gross negligence to drive my car without my splints. I can only plod around the house without them. If I'm gardening or needing to bend, the motion forward is restrictive and if you are wearing the Toe-Offs they may delaminate. So for such activities I tend to use the plastic AFOs although the gait is not as elegant. I work in business where I wear a suit.

Megan described Stephen's gait when he first came for help as very flat-footed. You could always hear him coming with his feet flopping. With the "Toe-Offs" you could not hear this flopping of the foot and he walks with the normal heel-to-toe. Stephen reported he could wear more normal shoes.

Q. What about fatigue?

Stephen reported feeling less fatigued in the "Toe-Offs". Another member reported they had made an amazing difference to her walking.

Megan advised there was a type of AFO that was spring-loaded to actively bring the foot up. She mentioned there were many different types of AFOs to suit individual needs.

Q. Can it improve calf muscle weakness?

Megan advised that wearing AFOs did reduce the calf weakness otherwise experienced without them

Q. How often would a CIDP patient fitted with an AFO need to come back for a check-up?

R. In the beginning Megan would get them back within a month to check that all was well. Then it is usually a yearly visit although many don't return for a couple of years. They may then need some running repairs.

Q. What is PADP?

R. It is now called ANEP which is Aids And Equipment Program, the government funded scheme for people with chronic conditions. They pay, either in full or in part, for items such as wheelchairs, modifications to houses, splints, braces. It requires a doctor's referral. There is no asset test. Then you go on a waiting list, currently 12 months.

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## The IN Group News

### Cake Stall success

Our now annual Cake Stall held at Maling Road Canterbury on Saturday morning 11<sup>th</sup> May was another great success. A total of \$999 (including monetary donation of \$72) was raised from the sale of the many cakes, jams, biscuits, quinces, pumpkins, tomatoes donated by many of our members.

Our thanks to the three who manned the stall and made many cakes - **MARGARET LAWRENCE** (the initiator and main organiser of this fundraising feature), **BETTY GERRAND** and **BARBARA RIVETT**, as well as the many other contributors who included **DOROTHY BRENNAN**, **BRONWYN CLARKE**, **BARBARA CLIFFORD**, **ROSE-MARY MacQUALTER**, **RAE MALCOLM**, **JOYCE MONTGOMERY**, **JEAN STURROCK** and **LUCY TIDBURY**.

A leaflet about The IN Group, prepared by Rosemary Macqualter, was appreciated by customers who received it with their purchase.

## Winter Social Luncheon Winter Social Luncheon

**Margaret Lawrence** will again be our hostess for The IN Group **Winter Social Luncheon** to be held from noon on 16<sup>h</sup> June at her home 26 Belmont Street, Glen Waverley. \$15 will provide a lovely luncheon of a choice of soups and cakes as well as raising funds for medical research.

An added attraction is that **LOUISE KLEIN** will give a talk on **LATERAL THINKING**. Thanks, Bronwyn Clarke, for the recommendation.

Some jams left over from the Maling Rd Cake Stall will be on sale.

## Shortage of Intragam

**Hospital Visit** Arising from a special committee meeting held on 4<sup>th</sup> March, a letter, **Grievous shortage of Intragam**, was faxed to both the Commonwealth and the Victorian Ministers of Health, with copies to the Heads of the Australian Red Cross Blood Service, CSL Blood Plasma and the Australian Association of Neurolog-ists. (This letter is printed on back of wrapper.)

Victorian Minister Hon John Thwaites replied giving a good rundown on the current situation. His government is spending \$58 million per annum as their share to ensure an adequate supply of Intragam. Whilst out-put of Intragam was increased last year by 5%, unfortunately demand has increased by 20%.

The reply from the Commonwealth Minister's office was also informative. A special meeting of ARCBS, CSL and government health authorities, held 29/4/02, provided a greater understanding of the demand for Intragam. (Mr Bordonaro, Manager of CSL Bioplas-ma has advised that The In Group fax, mentioned above, was very helpful to this discussion.) The main outcome of the meeting is that the National Health and Medical Research Council (NHMRC) is to review the AHMAC Working Party Report, both to assess the current unmet demand for Intragam so as to assist determining target levels for its production and also develop appropriate clinical guidelines for more uniform medical treatment. CSL has hopes that within 12 months patients should be receiving their prescribed Intragam amounts.

## GBS/CIDP Awareness Day 1st June 2002

The Council of GBS/CIDP Support Groups of Australia again set 1st June as our national Awareness Day. The IN Group issued a Media Release with the theme "**A Big Thank You to Blood & Plasma Donors**", hoping our appreciation will stir a media exposure. The Red Cross Blood Service and CSL warmly welcomed this expression of gratitude. (This Release is also printed on the back of the wrapper.)

The Release was e-mailed to the News Desks of "The Age", "The Herald Sun", "The Australian", the local "Progress Press" and to Dr Swan, the presenter of "Health Dimensions, the ABC TV 6.30pm Tuesday program. **STEVE CAMPBELL** had paved the way to Dr Swan by previously faxing him a persuasive letter.

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## **Film Luncheon**

Eight members enjoyed seeing "Gosford Park" and each other at the Balwyn Cinema plus the following basket lunch on 22<sup>nd</sup> April.

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## **Entertainment Books**

Ten of the new Greater Melbourne 2002/2003 Books that feature discount on dining, hotel accommodation, theatre, sports and much more have already been sold. When you buy a Book for \$55 (\$60 inc. postage) you are also adding \$11 to The IN Group.

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## **NorthEastern Cluster Group**

**VILMA CLARKE reports** this Group is increasing, with a few members having been re-diagnosed from GBS to CIDP. Their next meeting is in May.

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## **Support is the Name of Our Game**

### **New Members**

A warm welcome to new members **PAUL BEARDSLEY, LOU BETTIOL, JUSTINE FERRER (USA), CHRIS FISHER, CHRIS & JENNY GOOCH, STELLA HITCHCOCK (USA), BRUCE HUNTER, LEAH KOCH, IAN KRUSE, VAL MASON, NAOMI MOODY, JUDY MUNSTER, VALERIE NIXON (USA), TED & VAL PERRY, BARBARA PHILLIPPI, NOEL POTTER, KAREN SCALZO, DANIEL SMITH, JOHN SMITH, STUART VIZE, CHRISTOPHER WEIR, FRED WEST, STEVEN & LINDA WHEELER (USA), ROBERT WILSON.**

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### **Arranging Overseas Treatment**

When member **JO DAVIS** advised that she would need monthly plasmapheresis treatment when she visited her father in Nottingham UK, I e-mailed Glennys Sanders, President/Secretary of the GBS

Support Group (of the UK) to see what could be done. Glennys kindly advised the name and address of a neurologist of a Nottingham hospital that would be able to arrange the treatment. JHG.

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## Coping with GBS

*Hi, My name is Karen, I'm 23 and I am currently recovering from a bout of GBS. My story has actually not been all that severe ? on the net I have read far worse cases. I had some sort of virus, glandular fever was suspected, for about 2 weeks. Fever, aches, etc. Once the fever left I started to get the numb toes, the weak legs. 4 days after, I was admitted to Knox private hospital. They did the usual tests ? lumbar puncture, reflex tests etc and suspected GBS. I stayed in ICU overnight, not due to any problems but just for observation and also that was the only bed available in the hospital. The next day I was transferred to St Vincents Hospital. My legs were still weak but it was not progressing to my chest. I was there for 6 nights and given 24gm of Intragam daily over the 6 days. After 2 days treatment my toes felt less numb. The physio said my strength was getting better. I was walking normally halfway through the treatment.*

*I also developed Bell's Palsy while in hospital but with medication that is also getting better.*

*Now its 2 weeks after the initial numbness in my toes and I'm not 100% but I'm nearly there. My legs are nearly at full strength and my endurance levels are also nearly back to normal. I'm already back at work.*

*I thought my story may provide hope for some other patients that you encounter.*

*Regards, Karen Scalzo.*

Thanks for your helpful report.

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## A Thank you from the NorthEast

Dear Director, Just a short note to thank you for giving me the opportunity to join your Group. I would also like to thank **Vilma Clarke** from the N.E. Group for the literature she provided, especially the GBS booklet which threw a greater light on the virus (a lot more than the doctors). Also I have several discussions with **Jill Grimmond** which has been very helpful.

**Robert Wilson**, Bulgandra Station, Rand NSW.

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## Information Supplied via the Internet

The In Group posted GBS or CIDP booklets plus The IN Group brochure and latest newsletter to the following inquirers via the internet: **Australia:** Richard Byrnes (Vic), Trudy Schmidt (WA), Sandra Thyssen (Vic), Sonia Williams (Qld). **Overseas:** Debbie & Simon Cork (USA), Shirley Futrell (USA), Devora Griggs (USA), Sandra Janisse (USA), Carlo Lega (UK), Carolota Miller (USA), Angela Moody (USA), Mrs Tanks (USA).



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Sharna with Dr Kornberg and mum Susan

## **Our Researcher in RCH Good Friday Appeal**

**Dr Andrew Kornberg** is featured in the "Herald Sun" of 28/03, treating a child with a rare immune system brain disorder ADEM. Dr Kornberg has recently received CSL support to employ a neuro-muscular fellow to assist his research into GBS/CIDP which The IN Group also supports.

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