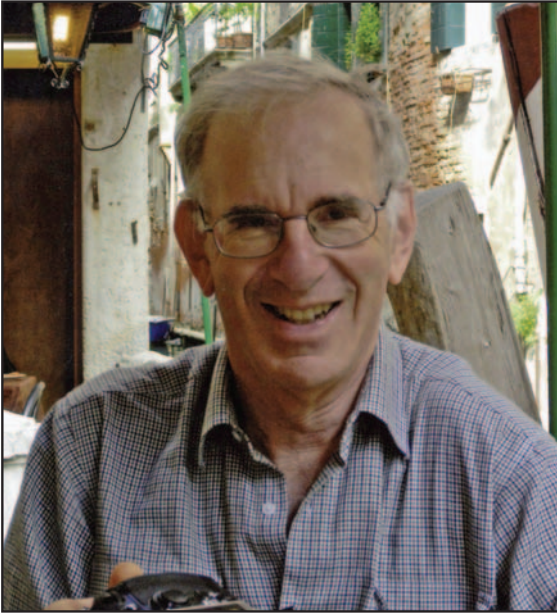


News+Views

Newsletter 63, November 2011



Dr Lindsay Haas

The NZDPN wishes to acknowledge the passing of Wellington-based Neurologist Dr Lindsay Haas who over the years provided highly skilled treatment for many dystonia patients. On 16 July 2011 The Dominion Post published an article about him and with permission from the Dominion Post and Tony Haas, we feature excerpts.

'Highly Skilled Neurologist Committed to Public Health System.' (Excerpts)

By Peter Kitchin DomPost 16/7/11

"For more than 20 years, Lindsay Haas, of Wadestown, was the highly regarded physician in charge of the neurology department at Wellington Hospital. ...In all, he spent 35 years on the hospital's books. He was a public health system doctor by choice, and an active promoter of the state's involvement in public health and a formidable representative of the interests of its staff.

Medicine is an enormous field, and Dr Haas could not have chosen a more complex field in which to specialise. Neurology, the science devoted to the study of the nervous system and to diagnoses and treatment of it when bits go awry, requires physicians to have observation skills of the highest order, and an intimate understanding of potential symptoms and signs, not to mention an understanding of

the way the nervous system is affected by various illnesses.

For the most part, the nervous system goes about its business without recourse to remedial treatment. It's a sophisticated wiring system of nerves through which electrical signals trigger the myriad jobs needed to receive sensory inputs, respond emotionally, make decisions and make muscles function.

When it is impaired, conventional activities most of us take for granted can begin to make us act in ways that can be mildly irritating or at worst, drawn out and even fatal.

It's as complex a business as the massive networks of nerves that inhabit every human. Dozens of tests may be in order, some as simple as the ability to feel the prick of a pin all over, or the tap of a rubber-headed tendon hammer, shocks to nerves to measure electrical activity in muscles and yet others of great complexity such as MRI scans.

...Dr Haas chose the neurology route soon after graduating from Otago University's medical school in 1965. Earlier, he had graduated with a degree in medical science so he was well-equipped for research when he enrolled at the National Hospital for Nervous Disease, Queen Square in London. The study itself required an exhausting degree of application, not to mention stamina. He had both, and would return to Wellington in 1974 as a consultant neurologist with new diagnostic methods and treatments, and later went on to lead teams and research.

Lindsay Haas was one of those rare people who could be accused of redefining multi-tasking. While running a battery of tests, for example, he could dictate letters, declare a new avenue of research, fire off information requests all the while treating his patient with the utmost kindness.

...Lindsay Haas was educated at tiny Mangamutu School and at Nelson College. He was a country boy with a difference. He was used to books, to learning and was a hungry learner; they were attributes that were second nature to him throughout his life.

In later years, he resumed his Nelson College interest in photography; his work was of exhibition quality. He was also a social animal, he entertained, he tramped, he skied, he was a classical music buff and read voluminously. His wife, retired paediatrician oncologist Dr Margaret Lewis, and their three daughters survive him.

[Sources: Tony Haas, Peter Hatfield, Suzanne Blumhardt, David Abernethy and others.]

Living in the Moment

Practice Mindfulness to Reduce Stress

By Karen K. Ross, PhD. (Reprinted with permission from the Dystonia Medical Research Foundation. *Dystonia Dialogue*, Winter 2010, Vol. 33, No. 3)

While stress does not cause dystonia, feelings of anxiety can certainly make symptoms worse. Taking a few moments each day to focus on relaxation can improve your overall well being and may help keep dystonia symptoms under control.

Mindfulness the practice of living in the present moment. Mindfulness meditation is a practice that uses focusing on the breath as a way to calm the mind and body. The primary focus is your breathing. However, the primary goal is maintaining a calm, non-judging awareness, allowing thoughts and feelings to come and go without getting caught up in them.

Here are the basic steps of mindfulness meditation:

- Sit or lay comfortably, with your eyes closed and, if possible, your spine reasonably straight.
- Clear your mind and direct your attention to your breathing. Observe your natural breath without trying to change it.
- When thoughts, emotions, physical feelings, or external sounds occur, simply acknowledge them and let them go without judging or getting involved with them.
- When you notice that your attention has drifted off and your mind becomes engaged in thoughts or feelings, simply bring it back to your breathing and continue.
- Start by trying to meditate for 3-5 minutes, and gradually try to progress to 20-30 minutes.
- It's natural for thoughts to arise and for your attention to follow them. No matter how many times this happens, keep bringing your attention back to your breathing.

Relaxation CDs for the Dystonia Community

Vice President of 'Support', Karen Ross, PhD has created two original relaxation programs available on CD:

- Calming the Body, Calming the Mind
- Mindfulness Meditation for Stress-Reduction

Both CDs are available for purchase at www.dystonia-foundation.org or at <http://shopping.netsuite.com>

For additional relaxation and meditation practices to combat stress and feelings of anxiety, visit <http://www.dystonia-foundation.org> under :Living with Dystonia.

Genetic Researchers Need Your Help ...and a Little Blood

(Excerpt from 'Dystonia Dialogue' DMRF Winter 2010, Vol. 33, No. 3.)

Finding genes associated with dystonia may be the key to understanding how to better treat or cure the disorder. A collaborative team from Beth Israel Medical Center and Mount Sinai School of Medicine is conducting a study aimed at finding these genes. If there are two or more living individuals in your family with any form of dystonia you may be eligible to volunteer for this important study. Participants will be asked to complete a short questionnaire and

medical record release form, sign study consents, and give a blood sample, which may be done locally. Your information will be kept strictly confidential.

You can help to unlock the mysteries of dystonia.

For more information please contact:

Deborah Raymond, MS

Department of Neurology, Beth Israel Medical Center

Email: draymond@bethisraelny.org



2012 Seminar and AGM

It has been decided by the Executive Committee to hold the 2012 Seminar and AGM at Hamilton on Saturday 12 May, and the Conference Centre at the Hamilton Airport Motor Inn has been selected as a suitable venue. This site is a 5 minute walk from the Airport terminal, and there is also plenty of parking for motorists.

Hamilton Airport Motor Inn contact details are:

Ph: 0800 106679 email: conferences@airportinn.co.nz

website: www.airportinn.co.nz

Once again, for current financial members as at 5 Nov 2011, the Network will subsidise accommodation up to \$130 for a maximum of one night. To receive this subsidy, members should contact the Motor Inn direct, book their room, pay for it when attending and submit a receipt to the Network for reimbursement.

Full details of the Seminar programme and AGM agenda will be published in the Feb/March Newsletter.

Message Boards

(Excerpt 'Dystonia Dialogue' DMRF Winter 2008, Vol, 31, No. 3.)

People use message boards to post typed messages and invite public responses or private emails from others who view the message board. The Online Dystonia Bulletin Board (BB) has thousands of members from all over the world. Beverly Wagner of Maryland was diagnosed with dopa-responsive dystonia at the age of 42 after a lifetime of being told she had cerebral palsy. She explains, "I love this bulletin board. The people here have an incredible understanding of what I go through on a daily basis that not many people in my life understand completely."

The Online Dystonia Bulletin Board provides insight to not only people with dystonia and their family members, but others as well. Karen Haag in Michigan explains, "My doctors often come to this BB to read what we are posting and to see how we deal with our dystonia."

The Online Dystonia Bulletin Board and Dystonia Chat Room can be accessed at www.dystonia-bb.org/forums/asd/

A message board for individuals with dystonia about deep brain stimulation surgery is available through Yahoo!

Groups at

<http://health.groups.yahoo.com/group/DBSforDystonia>

Dystonia Information Display

This work continues and in July the Whanganui Public Library hosted a Dystonia information display for one week.

*Whanganui Library Foyer,
July 2011.*



Free Tips for 'ST's' (those with Spasmodic Torticollis).

(Reprinted with permission from Abbie Brown, at STclinic.com)

NZDPN Editor's note: *As many of our members do not currently have computer access (some 67 individuals on our newsletter list have no email address) and/or their disability restricts their network usage, we reproduce from time to time, internet articles which may assist them in their daily lives.*

About her ST Recovery/Management Program, Abbie writes: "ST's have complex physical problems with varying degrees of involvement, so we custom the program to each individual person, according to their own situation and the way their ST manifests. For example, some clients can do almost all the exercises, some only a few; some can do the standing ones standing, others have to do those lying down to have the exercise be helpful and not be counterproductive. Re. the exercises, almost always the side to which your head turns is the "short side" (your muscles are more contracted on that side which pulls the head over and usually pulls that shoulder up.) You need to exercise to stretch both sides of the back (as ST almost always manifests also in the back) and neck with more emphasis on your short side. If you lean one direction and turn the other, you probably have a bilateral shortness and need to work both sides evenly. One of the keys is trying to stand erect, back of the neck flat, chin down, shoulders squared, and your head and neck stacked on top of the trunk of your body. (I.e. a "military brace" position) not jutting out in front, which is so typical with ST's. You can see how this feels if you will lie down on the floor on your back, knees up. Now try to touch the floor with the back of your neck. You won't be able to, but try. You'll see that will force your chin way down. Now try to imitate that position standing up or sitting - that's the Military Brace position, and most exercises are done in that position. The chin should never be up with the head reared back. So if you are lifting a weight over your head, you can stand very straight in a military brace position (back of neck flat and chin down, shoulders squared), knees slightly bent and raise the weight over your head and down several times, maintaining the military brace. Think the exercise into the back of your head and neck - i.e. try to feel it there. You can begin with a 5 or 10 lb. bell or whatever is challenging for you. Then apply the same principal to other stretching exercises. The trick is to daily stretch those muscles and get them flexible and of equal length. Work in slow motion and hold the extension, breathing into it.

Then you should be getting some daily massage - maybe

from a family member. Sit in a chair sideways so your back is exposed, forearms on your knees, head hanging down, and have the person doing the back rub stand in back of you and use the heel of his or her hand (with some massage oil or hand cream) or knuckles and begin at where the bra line would be for a woman and move up the muscles on either side of the spine and pinch the muscles. [The thumbs can be used] as well or knuckles to work on the muscles in the back, across the upper shoulders and at the bony ridge at the back of the head, and you'll find you are probably very tender there. Use the knuckles to push up the back of the neck and push up under the bony ridge at the back of the head and hold a few seconds. Myra Jacob, Clinic Board member and LMT has written a book, Torticollis Massage Guidebook with an 18 minute DVD. See her site: <http://www.torticollismassage.com>

...What you are doing over time in this recovery program at S.T.R.C. is creating a new reality for your body - a new muscles memory, new brain pathways, restructuring musculature and postural realignment, so that eventually, that new reality, or new you, will begin to dominate, forcing the symptoms of S.T. into dormancy, and you can come into what we call a state of ongoing recovery. I personally have not seen a medical professional regarding my S.T. since 1983, take no meds for S.T. and walk in daily recovery via this program." ...Read more about Abbie's program and her recommendations, at: www.stclinic.com

Pin/Magnet Badges

For some, these approx. 3.5 cm x 5.5 cm 'badges' can be especially useful at work or in front-line situations. The badges are available with either a pin attachment or a magnet attachment. Costs: Pin Badge: \$11 per badge plus \$2 postage. Magnet badge: \$13 per badge plus \$2 postage. Contact Ross Farquhar, Phone: (06) 353 1915 or email: rosstf@vodafone.co.nz

Pin Badge: \$11 per badge plus \$2 postage
Magnet badge: \$13 per badge plus \$2 postage



Sponsors/Charitable Donors

Our very grateful thanks go to our sponsors and charitable donors. We wish to acknowledge and thank Allergan, JR McKenzie Trust, and NZ Lotteries, for their financial support, which enables us to provide information and assistance to members.

Deep Brain Stimulation

Further to the article on Deep Brain Stimulation (DBS) in our July newsletter, Robyn Mcilvar of Sydney, who had DBS surgery 18 months ago reports that "for me it has been life changing it has given me back quality of life... I have about 65% improvement and couldn't be happier. DBS is not a cure and they don't claim it to be." Robyn is happy to answer any questions people who are considering DBS may have about the surgery.

Email: robyn_mcilvar@hotmail.com

Helpful Websites

American Dystonia Society

www.dystonia.us

Bachmann-Strauss Dystonia & Parkinson Foundation

www.dystonia-parkinsons.org

Benign Essential Blepharospasm Research Foundation

www.blepharospasm.org

Brain Foundation Australia

www.brainaustralia.org.au

Care 4 Dystonia Inc

www.care4dystonia.org

Dystonia Coalition

<http://rarediseasesnetwork.epi.usf.edu/Dystonia/index.htm>

Dystonia Medical Research Foundation (USA)

www.dystonia-foundation.org

Dystonia Society (UK)

www.dystonia.org.uk

Movement Disorder Virtual University

www.mdvu.org

National Spasmodic Dysphonia Association

www.dysphonia.org

National Spasmodic Torticollis Association

www.torticollis.org

New Zealand Dystonia Patient Network Inc

www.dystonia.org.nz

Spasmodic Torticollis Recovery Manual

www.STclinic.com

ST/Dystonia Inc

www.spasmodictorticollis.org

Tyler's Hope

www.tylershope.org

WE MOVE

www.wemove.org

Letters to the Editor

Items of interest and letters to the Editor welcome. Please forward to Ross Farquhar. Phone: (06) 3531915

Email: rosstf@vodafone.co.nz

Disclaimer [printer - blue square please]

Nothing in this newsletter is intended to serve as medical advice on dystonia. The NZDPN recommends that you consult your own doctor(s) and other health professional(s) regarding your diagnosis and treatment. We acknowledge and thank Allergan, JR McKenzie Trust, and NZ Lotteries, for their financial support.

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Our 3-fold mission is:

- To support dystonia patients with information, advice and networking opportunities
- To increase awareness about dystonia - both among the medical community and the general public
- To encourage and facilitate research, with the aim of seeking better treatments, prevention, a cure



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Donations and membership:

The NZDPN is a Health Promotion Association registered with the New Zealand Charities Commission. As well as encouraging research into dystonia and promoting awareness of our condition, our mission is to provide information and support to all those affected by dystonia. We are a 'grass-roots' organisation. Most of our leaders have dystonia themselves, and we are entirely reliant on donations, membership contributions and other charitable grants.

The Network invoices members once each year, in February for the Annual Subscription. Membership is \$20 per annum and applies for the calendar year in which the payment is made. Donations are also welcome and are tax deductible.

You may wish to use internet banking and directly deposit into the NZDPN's bank account:

**NZ DYSTONIA NETWORK
NATIONAL BANK, WAIKANAE
06-0577-0110415-00**

When using internet banking please complete the 'Code', 'Reference' or 'Particulars' fields to let us know whether a deposit is a donation or for membership. Alternatively, if you wish to send a cheque to the NZDPN please send contributions to:

The Treasurer, NZDPN, P O Box 305 375, Triton Plaza, North Shore 0757

PLEASE NOTE - All receipts will be automatically issued for amounts of \$100 and over. Receipts for lesser amounts will only be issued if you request same.

Your NZDPN Executive Committee is:

Chairperson:	Ross Farquhar
Deputy Chairperson:	David Mitchell
Network Manager:	Philippa Hooper
Treasurer:	Linda Jones
Secretary:	Alex Tate
Committee:	Jan McCabe Roger Terry Shirley Henderson

Support Group Leaders

Auckland:	Rowena Pryor and Faye Bagosi David Mitchell
Waikato:	Delia Wilson
Hawkes Bay:	Roger Terry
Manawatu:	Ross Farquhar
Christchurch:	Barbara Murrell
Timaru:	Alice Denne
Dunedin:	Chris Spooner

Support Group Leaders can be contacted by Emailing info@dystonia.org.nz or by writing to the Network at New Zealand Dystonia Patient Network, P O Box 305 375, Triton Plaza, North Shore 0757.

Website: www.dystonia.org.nz

Database Manager: David Barton

Info Line Officer: Alison Fitzpatrick


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