



## MND Tasmania News

November - December 2008

MND Tasmania  
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### Patron

Lady Sallie Ferrall

### State Committee

President: Tim Hynes

Vice-President: Joyce Schuringa

Treasurer: Dora Hugo

Secretary: Denis Lyne

Care Advisor: Anna Nicholas

Lyle Sydes

Kate Barnett

Public Officer: John Hughes OAM

Northern Support Group: Mary Erickson

### Regional Advisor

Jennene Arnel

### Support service

The MND Associations of Victoria and Tasmania work together to improve support for people with MND.

- Information and support by telephone 1800 806 632, Mon - Fri, 9 am-5 pm.
- Referral to Tasmanian support services.
- Information kits.
- Free membership of MND Victoria and MND Tasmania for people living with the disease.
- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.
- Telelink meetings for people with MND, carers and past carers.

### Newsflash

Our President Tim Hynes has been working strategically with MNDVic CEO Rodney Harris and in September he announced a new initiative for people with MND and their families in Tasmania:

I am pleased to advise that we have been successful in sourcing funds for the establishment of a MND Tasmania Regional Advisor service.

Through approaches to philanthropic trusts, we have been successful in securing a grant of \$40,000 per year for three years.

I have advised the Department of Health and Human Services Tasmania of our intentions.

Funding will support a 0.3 EFT position based in Melbourne. This equates to approximately 75 working days per year.

Jennene Arnel, well known to many members, has been appointed to undertake this role reporting to Rod Harris, CEO, MND Victoria. She is currently developing a program of visits over the next 12 months, along with activities to influence local service providers. She will be implementing the Regional Advisor model documented by MND Victoria

Essentially, the first year will involve physical visits to Tasmania followed by office-based work to support clients. The project will formally start on 1 October, and the first month will entail establishing systems and processes, undertaking background work, development of information, and making early contact with clients. This will be followed by a two-week visit to clients and service providers in Tasmania. There will be office based follow-up in December and January and then a one week visit in February. The program will then progress on the basis of alternate month visits to Tasmania, along with office-based activities to support client needs and referrals. Clearly, we will maintain flexibility in the approach and ensure that we are able to adjust the program to address emerging issues. The current plan is to keep about 10 days in reserve to react to issues and to ensure we maintain relationships with DHHS and service providers.

MND Victoria and MND Tasmania have high expectations that this project will be the start of a new direction to support people living with MND in Tasmania, and will attract government funding to ensure its longevity.

Planning has progressed since September and MNDTas will provide additional support of \$5,000 in the first 12 months. Jennene Arnel has booked visits to southern Tasmania in the week commencing on 10 November and in northern/northwest Tasmania commencing 17 November.

She is arranging to meet with all members who have MND or Kennedy's disease, MNDTas Committee members and a number of key health workers and related service providers.

### **People in Tasmania who have MND**

We currently have 20 members in Tasmania who have been diagnosed with MND. Seven of these people live in the north, six in the northwest and seven in the east and south of the state. Three members are living in residential care facilities.

We also have two members who have been diagnosed with Kennedy's disease. As there is no specific diagnostic test for MND at this time, the processes to diagnosis can be drawn out and difficult. Some people who have been diagnosed with MND have this diagnosis changed at a later time. Kennedy's disease has some features which are similar to MND and as there is no Kennedy's support group in Tasmania, we welcome people whose diagnosis is Kennedy's disease as members.

Bill Braithwaite, our longstanding Immediate Past President passed away in January this year. He always advised people to be rigorous in pressing for diagnostic tests as his diagnosis of Kennedy's disease was confirmed after a muscle biopsy although he had been told many years previously that he had MND.

### **Local contact with other people with MND**

If you would like to be in touch with other people with MND in Tasmania and who live near you, please contact Jennene Arnel at MND Victoria on 1800 806 632.

### **Northern Support Group**

Mary Erickson is the contact person for this group. She may be contacted on 1800 806 632 (message). Meetings are held on the last Monday of each month at 11am at the John Grove Centre, Howick Street, Launceston.

### **New Members**

We welcome new members:

T. & G. Good (NW); B. & S.Keogh (S).

### **Vale**

Our sympathy is with the family and friends of our member Jeanette Males.

### **Donations**

Donations have been gratefully received from B. & S. Keogh and from donors in the Northwest via John Hughes.

Mary Erickson and the Launceston Support Group have also been busy. Donations have been received at the Group's meetings from a number of donors including M. Viney, F. Saltmarsh and L. Jestrinski. Some supporters ran an expo of creative memories scrapping incorporating information about MND with 10% of the proceeds going to MND Tasmania.

### **Superannuation**

The Australian Tax Office website [www.ato.gov.au](http://www.ato.gov.au) provides information about early access to superannuation for people with terminal medical conditions. Information about the legislation allowing tax-free lump sum payments and accessing super tax-free can be found at [www.ato.gov.au/distributor.asp?doc=/content/Content/00158639.htm](http://www.ato.gov.au/distributor.asp?doc=/content/Content/00158639.htm) (Thanks to MNDA SA for this information, taken from their Newsletter September 2008.)

### **Talking with Young People about MND**

These packs are designed to strengthen communication with children who have a parent recently diagnosed with MND. There are six booklets for parents, 8-12 year olds, teenagers, friends, schools and health professionals.

The pack is available via our helpline number and they can also be downloaded from the MND Australia website at:

<http://www.mndaust.asn.au/just-been-diagnosed/>

### **Motor Neurone Disease: aspects of Care for staff of residential facilities**

This publication is also available via our helpline service. The information is practical and authoritative and may also be of benefit to people who live in their own home.

### **Equipment: Communication**

The Lightwriter is a communication device supplied by Zygo Australia. It has a keyboard, a display screen and a voice output. MNDTas has four of these machines available for loan.

There are a variety of personal alarm or emergency call systems and telephone adaptations, which are suitable for people with motor neurone disease.

Information and assistance about such equipment can be obtained from the Independent Living Centre Tasmania: 46 Canning Street, Launceston, 7250. Telephone: 1300 885 886 [www.ilctas.asn.au](http://www.ilctas.asn.au)