



PSP Australia (Progressive Supranuclear Palsy)

Providing information & support to people diagnosed with PSP, their family members, carers and health professionals

April 2010

Honorary Medical Advisor:
Assoc. Prof. David Williams.
MBBS, PhD, FRACP.

Key contacts PSP Australia
Anne Mooney (Convenor)
Ph: (03) 9568 7748
damooney@bigpond.com

Shirley Milne
Ph: (03) 9503 9057
glaciarium@optusnet.com.au

Telephone Support:
Melbourne Area
Anne Mooney: (as above)

Shirley Milne: (as above)

Country Victoria
Bruce Eva
(03) 5853 1006

Pam Collins
(03) 5472 2783

New South Wales
Alice McPherson
(02) 4421 5202

Kate Blizard
0412 534 908

Claudia Berry:
(02) 9997 3927

Website
www.psp-australia.org.au

Address for correspondence:
PSP Australia,
C/- 5/15 Heath Avenue
OAKLEIGH VIC 3166

Minutes from PSP Australia/Support Group Meeting: Thursday 1st April 2010

Present: We had 19 members present, all contributing to a very informative meeting.

Apologies:
Shirley Milne, Doreen Barr

In Memoriam:
Mr Leo Tobin and Mr John Welling. We extend our sincere condolences to their families and friends at this sad time.

Correspondence in:
Letters received from:
The Alfred Foundation,
Tobin Brothers and
Assoc Prof David Williams

Correspondence out:
Nil

Donations:
Tobin Brothers \$1600.00
Landpartners \$110.00
Steven & Linda Douggie
\$125.00
Camberwell Girls Grammar
\$253.55

Accounts to be paid:
Nil

General Business:
One of our members, Lynne Shires, whose husband Ron has PSP, is on the staff of

Camberwell Girls Grammar. After speaking with the head of Junior School, Glenda Bushell, it was decided that a fund-raising day for PSP could be organized with the support of staff, parents and students. Lynne addressed assembly on 22nd February and explained to all present the nature and effect that this terrible disease has on the families that it touches. Following on from this a free dress day was held on 22nd March with a gold coin donation towards PSP. The girls raised \$253.55 which Lynne presented to David Williams at our meeting on 1st April.

PSP Australia Support Group sincerely thank the staff, parents and students for their wonderful effort and support of PSP.

Tony Haydon has advised us of the following site regarding the new Productivity Commission instigated by Mr Kevin Rudd. The Commission is asking for interested persons to register their interest in an inquiry into a long-term care and support scheme for people with a disability in Australia. The inquiry will begin in April 2010 and report by July 2011. By registering your interest you will be kept informed of any progress that is made.

The link is as follows:
<http://www.pc.gov.au/projects/inquiry/disability-support>

Round the table chat:

Please be aware that all hints and advice contained in this newsletter should be referred to your own doctor or health worker.

As we know, every PSP sufferer responds to different treatments in different ways.

We were very fortunate to have Assoc. Professor David Williams as our guest at the meeting on 1st April.

As you know, David is a leading world authority on PSP and his research team at The Alfred is working with PSP teams around the world to find out the cause of PSP and to one day effect a cure.

David spoke of his research and there followed a lively discussion regarding this. Issues discussed are as follows:

There is an international trial being run at the moment using a nasal spray. The trial will start in Australia in June of this year.

Dr Connie Luk, a researcher from the UK has just been in Australia working with David on the abnormal build up of 'tau' in the brain of PSP sufferers See her report attached.

Melbourne Hospital is studying eye movement or the lack of same.

The study of spinal fluid taken from PSP sufferers is ongoing as is the study of genetics in PSP. Aggressiveness in people with PSP is thought to be due to several different genetic factors

The mechanics and deterioration in walking and the resulting falls are being studied by a separate group of researchers,

Neurologists are also studying the thought processes of PSP.

Ways in which we can help with research and making awareness of PSP more noticeable in the public arena:

Contact the health editor of your local newspapers and tell them your story. Papers love a good script.

Should you wish to be a part of Davids' research and do your bit to find a cure please contact Anne Mooney on 03 9568 7748 or email damooney@bigpond .com. with your contact details. Anne will then pass this information on to David.

THOUGHT FOR THE DAY

"Never miss an opportunity to give encouragement"

HOW TO SAVE A LIFE

St John Ambulance is running First Aid Courses for carers. Carers will learn essentials such as: CPR, First Aid for injuries from trips and falls, and how to assist someone choking. If you are interested, enroll via the Commonwealth Respite and Carelink Centre on: 1800 052 222 or St John's Ambulance on 1300 360 455. If you are eligible to receive financial assistance you can complete the course for \$160. For more information contact St John Ambulance: 1300 360 455.



PSP Australia is pleased to announce that it now has its own YouTube Channel where videos can be watched from your personal computer—whenever you choose!

YouTube is a public website that allows users to post and share videos and resources, footage and information from around the world can watched for free.

Currently, the PSP Australia Channel features the main presentations from last year's ***PSP Allied Health Professionals Day***.

This will be a wonderful resource for health professionals involved in the care of people living with PSP. They will be able to access this valuable information from anywhere in Australia, at their own time, and from their own workplace – for free!

The PSP Australia Channel can be accessed in 3 ways:

1. Direct by typing www.youtube.com/australiaps into your browser
2. Go to YouTube (www.youtube.com) and then type in 'PSP Australia' into the search box
3. Go to PSP Australia (www.psp-australia) and click on the link/icon to the PSP TV page (available shortly)

Keep an eye on the PSP TV channel as more and more resources are made available and spread the word.

Important note: As with any information posted on the internet, YouTube features videos uploaded by anyone and everyone, so we encourage you to be careful of what you watch and stick to material posted by reputable organisations.

PSP Notice board: News, Events, Updates

WE NEED YOU!

PSP Australia is growing significantly in response to the increasing need.

There is much work to be done to ensure the ongoing provision of support to our members and the wider community and in order to raise funds and awareness.

As a result, PSP Australia (based in Melbourne) is now seeking additional support in the following areas:

- Publicity,
- Newsletter,
- Financials, and
- Fundraising

Do you have skills, time, energy and enthusiasm to make a difference to people with PSP?

Are you able to volunteer to help in an ongoing capacity in any of the above areas?

Please contact Convenor Anne Mooney for further information: (03) 9568 7748 or email: damooney@bigpond.com

Building our networks and our infrastructure will ensure we are able to continue to assist those who are challenged by PSP and their families.

NEW DRUG MAKING IMPACT OVERSEAS

Allon Therapeutics announces davunetide receives FDA Fast Track Status for treatment of PSP.

The pharmaceutical company announced recently that its lead neuroprotective drug candidate, [davunetide](#), has been granted Fast Track status from the United States Food and Drug Administration (FDA) for the

treatment of PSP.

Fast Track status is designed to facilitate development and expedite review of a drug candidate that treats a serious or life-threatening condition and addresses an unmet medical need.

[Gordon McCauley](#), President and CEO of **Allon**, said the Fast Track status is an important milestone for the Company and validation of the desperate need for therapies in this debilitating disease where **davunetide** has such potential.

“Fast track status provides for early and frequent communication between the FDA and **Allon** to resolve questions and issues quickly,” said McCauley. “It will ensure that we work with the FDA to gather the critical data needed for approval.”

Fast Track also provides for “rolling submissions” in which sections of a new drug application (NDA) can be submitted and reviewed as they are completed rather than the typical process in which review begins only after the submission of the last section. Additionally, **Allon** may request that **davunetide** be considered for priority review, and if accepted would result in a six-month review instead of the standard ten-month review.

Allon announced January 12, 2010 that the FDA has granted Orphan Drug status to **davunetide** for the treatment of PSP treatment in the United States.

(the above article is taken from: www.allontherapeutics.com)

Managing Symptoms of PSP: Eye Movement/Vision Problems

This Help Sheet gives further information about the problems experience by people with Progressive Supranuclear Palsy (PSP for short) in relation to eye movements and vision. It outlines treatments and strategies for managing these problems. The information here is presented as a guide; it is important to discuss all symptoms and management strategies with your neurologist and other health professionals.

PSP is a rare neurological condition affecting the parts of the brain that control walking, eye movements, balance, speech and swallowing. PSP has a wide range of symptoms, but few people experience them all and symptoms vary from person to person. It is a progressive condition, meaning that the symptoms tend to worsen over time. However the severity and rate of symptom progression varies widely.

Difficulty controlling the muscles of the eyes is a common symptom of PSP. This problem generally appears later in the condition, on average three to five years after the walking problems. The associated vision problems cannot be corrected with eye glasses.

The most common vision problems include:

- Double vision, tunnel vision or blurred or misty vision due to problems moving the eyes.
- Difficulties in moving or aiming the eyes properly, making reading and driving difficult.
- Inability to maintain eye contact with others, giving the mistaken impression of disinterest or of a memory or thinking problem.
- Difficulties in looking down, causing problems with walking as well as with activities such as cutting food and guiding it to the mouth.

Treatments for managing common eye and vision problems include:

Special glasses with prism

lenses. These can help some people who experience difficulty looking down. Unfortunately, because people with PSP also have difficulty directing attention to low objects, these glasses are not always successful.

An eye-patch or taping over one lens may occasionally help to reduce double vision problems.

Artificial tears should be used to keep the eyes moist. They come as eye drops that can be used during the day. They also come as an ointment or gel which is useful overnight if the eyelids don't fully close.

Eye sprays are available, which may be sprayed onto closed eyelids as an alternative to using drops.

Less common eye and vision problems include:

- Problems with eyelid movements, including difficulty opening or closing the eyes. Some people experience involuntary closure of the eyelids or involuntary screwing up of the eyes, known as blethrosptasm.
- Slower frequency of blinking, which can lead to dry eyes, irritation, infection, and ulceration in extreme cases.

Sometimes the eyes water but the tears trickle from the corner instead of washing across the eye, so the centre of the eye remains dry.

- Difficulty tolerating bright light, especially bright sunshine.

Treatments for managing less common eye and vision problems include:

- **Sunglasses** that wrap around, or tinted lenses that can help with sensitivity to bright light.
- **Botulinum toxin** (Botox® or Dysport®) that can be injected into the eyelid to prevent the muscle from contracting, which helps avoid the involuntary closing or screwing up of the eyelids. Botox needs to be repeated every 3 or 4 months. Your neurologist can help to

arrange this treatment.

Other strategies for managing eye and vision problems

Eye and vision problems can also be managed with strategies such as removing low objects, particularly trip hazards such as rugs and low coffee tables. It can also help to place items such as call buzzers, food and drink and the television control within the field of vision. Remember also to take into account the limited direction in which the person with PSP can look and arrange items such as TV, books and pictures accordingly. An eye specialist, or ophthalmologist, can assist further if eye and vision symptoms are particularly severe.

Services for people with vision problems Vision Australia

provides a diverse range of services for people who have low or no vision and most services are provided free of charge. Specialist staff can assess your vision and provide services based on individual needs. Its library has a wide range of print alternative books, newspapers and magazines available free for loan through postal delivery to members across Australia. For more information, contact the national contact centre of Vision Australia on 1300 84 74 66 or visit www.visionaustralia.org.au Your **local library** will also have a selection of 'talking books' that you can borrow.

For further information about living with PSP, including the full range of PSP Australia Help Sheets, visit: www.psp-australia.org.au For PSP information and support phone Parkinson's Australia on 1800 644 189

This information is taken from the PSP Australia Information Kit. © PSP Australia

Remember: treatment options are evolving all of the time and it is important to regularly discuss the latest treatment options with your neurologist.

■ New members are warmly welcomed. If you would like to come along to a meeting, visit our website, or speak to a carer, our contact details are listed on the front page.

Next Meeting:

Our next meeting will be on Thursday, 3 June, 2010 at 10.30am.

PLEASE BE ADVISED

Support Group meetings take place on the **first Thursday of every second month.**

Scheduled meeting times for 2010 are as follows:

- 3 June
- 5 August
- 7 October
- 2 December

Venue: The office of Parkinson's Victoria: Kingston Centre, Corner Warrigal and Kingston Roads, Cheltenham Victoria.

We hope to see as many familiar and new faces as possible.

If you are unable to attend, you are welcome to contact us with any thoughts, stories or queries which may be included in our next newsletter.

Newsletter contributions Welcome

Contributions for inclusion in the ***PSP Australia Newsletter*** are welcome and we encourage and invite anyone with a story, poem or comment to **post or email** it to ***PSP Australia*** (contact details on the back of this edition). This

ensures the newsletter represents all members of our community.

Please ensure you provide your contact details (name and phone number/email address). Articles can be featured anonymously on request.

We especially welcome contributions from members who are unable to attend ***PSP Australia Support Group*** meetings in the hope that, by contributing and 'having their voice heard', they will continue to feel they are a part of our community.

Rib Ticklers' Corner

Paddy and Mick are walking down a street in London . Paddy happens to look in one of the shop windows and sees a sign that catches his eye.

The sign said: "Suits £5.00 each, Shirts £2.00 each, Trousers £2.50 per pair".

Paddy says to his pal, "Mick, look! We could buy a whole lot of dose, And when we get back to Ireland we could

make a fortune. Now when we go into the shop, you be quiet, OK? Just let me do all the talking, cause if they hear our accent, they might not be nice to us. I'll speak in my best English accent."

"Roight y'are, Paddy, I'll keep me mouth shut, so I will," replies Mick.

They go in and Paddy says, "I'll take 50 suits at £5.00 each,

100 shirts at £2.00 each And 50 pairs of trousers at £2.50 each. I'll back up my van and..."

The owner of the shop interrupts. "You're from Ireland , aren't you?"

"Well... Yes," says a surprised Paddy. "How der hell d' y' know dat?"

The owner replied, * "This is a dry cleaners".*