

# Thumbs Up



The Newsletter of the Motor Neurone Disease Association of South Africa

September 2009



*Why a picture of a scooter on our front page ?*

**The Mission Statement of the MND Assoc. of S.A. is  
“To provide and promote the best possible support for people living with  
Motor Neurone Disease, their families and carers and to raise public awareness.”**

## NEWS and REVIEWS

**PATRON**  
Aviva Pelham (M. Mus.)

**NATIONAL CHAIRPERSON**  
Dr. Franço Henning

**VICE CHAIRPERSON**  
Vivien O’Cuinneagain

**SECRETARY**  
Rina Myburgh

**MNDA of South Africa is a member of the International Alliance**

### ACKNOWLEDGEMENTS

**John Hall** for producing the design and DTP (desk top publishing) work.  
**Logo Print** (Maitland) for the printing of our magazine

**BECAUSE .....**

**We have great news - about a raffle with an exciting prize !**

*A red Gomoto Mojo 125cc Scooter, sponsored by Chandré Burger.*

- . This is a wonderful way to raise funds for the MNSA – get family, friends and acquaintances involved. With the fuel prices always on the up, what better way to get around !

**Where can you get wheels for R50 ?**

**Come on everyone – this is just too good to miss !**

**Tickets at R50 each are available from Liz on 082 878 3716  
or our office on 021 531 6130**

**The draw will take place on 4 December 2009 – just in time for Christmas.**  
(Registration, number plates and helmet for account of the winner)

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### CHRISTMAS CARDS

This year seems to have just flown past – Christmas is upon us and it's time for sending Christmas wishes - we ask your support in selling our Christmas cards, for which an order form with a picture of the card is attached.

## FROM THE CHAIRMAN'S DESK

### WHAT SHOULD YOU KNOW ABOUT PANDEMIC INFLUENZA A (H1N1) OR "SWINE FLU"

#### 1. What is pandemic H1N1 influenza virus?

The pandemic A (H1N1) influenza (flu) virus (germ) is a new member of the influenza virus family. Different influenza viruses cause the annual seasonal (winter) flu and, every few decades, a global pandemic. Influenza viruses infect birds and mammals and are usually species specific. Occasionally viruses cross over from one species to another. The pandemic A(H1N1) virus seems to have originated in pigs; however it is not spreading in pigs or from pigs to humans but only between human beings. Seasonal human influenza results in 6000 to 10 000 deaths every winter in South Africa and between 250 000 – 500 000 deaths globally, mostly in people over 65 and those with certain chronic medical conditions. In contrast, during pandemic influenza many of the deaths occur in younger and apparently healthy individuals

#### 2. How does the flu virus spread?

Influenza viruses are very infectious. It is almost impossible to stop influenza viruses, whether seasonal or pandemic, from spreading from person to person mainly through coughing or sneezing by infected people. Touching surfaces such as counters and door-knobs with influenza viruses on them and afterwards their mouth, nose or eyes can also infect people. This is why hand-washing helps. However influenza viruses are very infectious and all precautions can only decrease, but not eliminate, risk.

#### 3. How can the spread be limited?

You can reduce the risk of getting or spreading influenza by taking standard precautions:

- Wash your hands or clean them with alcohol-based hand rubs frequently, especially after you cough or sneeze and before you eat.
- Cover your nose and mouth with a clean tissue when you cough or sneeze, and throw the tissue in a rubbish bin immediately after you have used it.
- Alternatively, cough and sneeze into your sleeve.
- Avoid touching your eyes, nose or mouth, as you could infect yourself that way.
- Limit close (1 to 2 meter) contact with people who are sick with flu.
- If you get sick, stay at home and limit contact with others to keep from infecting them.

#### 4. Symptoms of an influenza like illness:

These are the same for pandemic and seasonal influenza. Typical symptoms include a sudden onset of high fever, cough, runny or stuffy nose, sore throat, headache, body aches, chills, tiredness, and lack of appetite. Some of those affected have reported nausea, vomiting, and diarrhea.

#### 5. What to do if you or your child has symptoms?

- Children and adults who are sick should stay at home for 7 days after your symptoms begin or until you have been symptom-free for 24 hours, whichever is longer.

- Drink clear fluids (such as water, broth, sports drinks, electrolyte beverages for infants) to keep from being dehydrated.
- Dishes etc. can be cleaned with hot soapy water.
- Throw away tissues and other disposable items used by the sick person in the trash. Wash your hands after touching used tissues and similar waste.
- Have everyone in the household wash hands often with soap and water, especially after coughing or sneezing. Alcohol-based hand cleaners are also effective.
- Avoid touching your eyes, nose and mouth. Germs spread this way.
- A person who is sick should recover in his or her own room as far as possible.
- If someone in your home is sick, as far as possible keep the person away from those who are not sick
- If a household member needs to come into the room keep at least an arms length away (1 to 2 meters) and do not sit on the bed.

#### 6. Take medications as prescribed:

- Take medications for symptom relief as needed for fever and pain such as paracetamol or ibuprofen. These medicines do not need to be taken regularly if your symptoms improve.
- Should you be prescribed antiviral medication take it as directed (where applicable – see 5 below).
- Continue to cover your cough and wash your hands often (even when taking antiviral medications), to prevent spreading influenza to others.

#### 7. When to seek emergency care

Emergency warning signs that need urgent medical attention include:

- Difficulty breathing or shortness of breath
- Pain or pressure in the chest or abdomen

- Sudden dizziness
- Confusion
- Severe or persistent vomiting
- Flu-like symptoms improve but then return with fever and worse cough

#### 8. Who should be tested?

Laboratory testing of people with a flu like illness is NOT generally recommended, as it is expensive and does not affect the treatment.

Laboratory testing is only recommended for patients with co-morbid disease and at risk for serious complications (see 10 below) and who have the symptoms and signs of severe acute respiratory illness.

#### 9. What medications are available to treat H1N1 flu virus infections?

The antiviral drugs oseltamivir or zanamivir are only recommended for those at risk of complications: see below.

#### 10. Who is at risk of complications

1. Persons (adults or children) with underlying medical conditions and who are receiving regular medical care for chronic pulmonary disease (including asthma) and cardiac disease (excluding hypertension), chronic renal and hepatic diseases, diabetes mellitus and similar metabolic disorders;
2. Individuals who are immunosuppressed (HIV-infected, on immunosuppressive therapy, etc.);
3. Adults and children who have any condition (e.g., MND, spinal cord injuries or other neuromuscular disorders) which make it difficult to cough and are at risk of inhaling respiratory secretions.
4. Residents of nursing homes, and other chronic-care facilities;
5. Pregnant women.

## FUNDRAISERS

Our fundraiser on 16 July at Theatre on the Bay, Camps Bay, was a great success, thanks to **Roxy Levy and Aviva Pelham** who sold the tickets - their efforts ensured a full house. Thank you to their family and friends who donated super prizes for the raffles and also the welcoming glass of wine on arrival ! Those who could not be at the show themselves, donated their tickets to enable others to enjoy the evening. We are so extremely grateful for the unselfish efforts of everyone involved, which resulted in us receiving the profit of R16,000.

Unfortunately the fundraising Dinner which was to have taken place on 1 August at the Foodbarn in Noordhoek, Cape Town, had to be postponed and a new date will be announced later.

In our previous Newsletter (May 2009) we told you about **Kerry Bluett** who ran the London Marathon in memory of her friend, Marina Beck, and raised R7,800. The final figure was actually R9,400 ! - we received further donations after our Newsletter went to print. That sure took a lot of running - thanks again Kerry.

We were just as overwhelmed as patient **Leon Keyter**, when we received an enormous donation of R70,700 from his friends and colleagues in Dubai, where he worked for several years, before retiring to Pretoria. We responded as best we could, but Leon's letter to them says it better:

*Dearest Friends,  
I am at a total loss for words and I have been agonising for the past few days at how best to express myself. My greatest fear is that whatever I say will sound inadequate in this unbelievable circumstance. To put it in plain language when I received the news from Lucy and Mark I was stunned and completely humbled. Fiona thought something was wrong as I wept and could not speak for a while with the enormity of it. My initial feeling of embarrassment has been replaced by a tremendous feeling of having been honoured by what you have all done, thank you very very much. My wish also is that other sufferers will benefit from this showing of generosity and kindness in my name. I hope in some small way to have touched your lives in the way you are all special to me.*

*It is very cold and wet in Pretoria but I persevere with my aquarobics and chiro sessions where I get thumped and wrenched! I am walking slightly straighter with the assistance of Mugabe my trusty walking stick but remain very weak and get breathless far too quickly. This means keeping the abuse to a minimum as escaping is largely out of the question for me!*

*In the meantime a stroke of good fortune has landed us a new home nearby on a single level, according to my family falling down two flights of stairs would not do me any good. We have a delightful garden surrounded by the home on two sides with easy access. Other advantages include electronic garage doors and 24 hour*

*embassy type security in a secure and secluded village atmosphere. The move will take a long time during which our old place will get some renovations prior to rental.*

*Dylan has finally moved out on his own to reduce his commute. Michelle and Paolo return in August from the UK and we may eventually get to use our garage for the purpose for which it is intended. She was here for two weeks for which I was extremely grateful to Paolo releasing the newlywed to see me.*

*One last time thank you all for your generosity, emails, phone calls and support.*

*Love and best wishes,*

*Leon and Fiona.*

Our sincere thanks go to our regular (monthly/quarterly) donors for their ongoing support, and to the following contributors:

In memory of Dr Francois Majoos: Chris Burger Fund, Dr Paul & Mrs Cheryl Salkinder, Erna Prins, Somerset Hospital Staff, and some anonymous donors.

In memory of Mark Agrella: Hannover-re Group, Lineas Holdings, L Forssman

In memory of Steve Malherbe: Saldanha Foods AND R Cleverdon, R Jowell, Dave Wright, Philip Shock Trust, Hilary Beningfield, Frank Seed, WR Terry, MG Norman, Sheldene van Zyl, L Chiappini, E Rood, G Subotsky, WGB Miller, Graham Milner, J Hindley & T Williamson, AL Steyn, NA Kelly, M Galimberti, as well Soroptomist International Cape of Good Hope Club (who donated funds specifically to enable us to purchase very much needed equipment) We also received "extra's" which came in addition to the membership fees, and quite a few "Anonymous" contributions and naturally would like to say to those concerned, many, many thanks.

*A smile is a way of writing your thoughts on your face  
Telling others that they are accepted, liked and  
appreciated*

## MAIL BAG

**Suzaan Stander of Boksburg, writes:**

Striving towards Independence .....

I was diagnosed with MND 4 years ago at the age of 33. I made a conscious decision early on to conserve as much energy as possible and opted for a wheelchair when doing distance walking, eg Shopping.

After about 8 months I wasn't able to push myself around anymore due to upper body muscle weakness. Liz Keth was kind enough to supply me with an electric wheelchair which I am lost without.

There was one big problem though: How does one

transport the wheelchair to your destination ? When visiting my sister in Belgium beginning 2007, I viewed an impressive wheelchair conversion on a local vehicle. Unfortunately the cost to import such a vehicle would be more than R450,000 – money I didn't have.

I engaged in an extensive search to find a company in South Africa who could accomplish the same conversion. I am very excited to inform you that "Woutago for Vehicle Conversions for Special Needs" was the only company based in East Rand that converted a

Volkswagen Caddy (5 seats) vehicle extremely professionally, very affordable and allows me to drive in without lowering my head.

Their contact details as well as pictures of the converted vehicle can be found on their website, [www.woutago.co.za](http://www.woutago.co.za) and their e-mail address is [wouter@woutago.co.za](mailto:wouter@woutago.co.za)

I hope this info can help anybody out there to achieve the same independence as it has given me. Thanks a million Wouter.

MND Regards, Suzaan Sander.



Tony Katzew, with MND Consultant Liz Keth, at the launch of his book "Happy Chappie"

### **"Happy Chappie"**

**Learning to live alongside Motor Neurone Disease, by Tony Katzew**

Tony Katzew is a 'boerejood' – a Jewish boy born in 1946, growing up culturally both Jewish and Afrikaans in Grasmere, a peri-urban area outside Johannesburg.

Tony often found himself in interesting places where unusual things happened. This collection of short stories is a delightful mix of incidents both humorous and touching which convey the flavour of living in South Africa in the 50s and 60s and beyond.

In 2002 Tony was diagnosed with Motor Neurone Disease. People who have this illness do not usually live beyond a number of years. Tony has defied the

odds, and he chronicles the journey he, his family and many friends have taken since then with engaging humour and realism. His positive spirit energises all those around him.

Tony lives at Hospice and is grateful for the important role the movement has played in the quality of life he enjoys there. He has been quadriplegic for over six years, but is able to carry on a 'normal life' within those constraints. He has been occupied writing these memories the last year, but takes an interest in TV sport and enjoys interacting with the Hospice staff, family and friends.

The book can be purchased from Tony on cell no 082 492 2527

*I bend but do not break  
~ Jean de la Fontaine ~*

### **"My Better Half and Me" - A love affair that lasted over 50 years.**

Acclaimed actor Joss Ackland and his wife Rosemary were married for more than 50 years, until Rosemary's death from MND in July 2002:

Throughout that whole time Rosemary kept a diary. She first started to put her thoughts to paper at the age of 15 and for the next 58 years, through a life which saw great highs and lows, she continued to write. In her final years, left immobile and unable to speak by MND, the diary became her only outlet for her feelings and emotions.

Her simple heart-felt writings were not meant for anyone else to read. During their long partnership, Joss never opened the diary. It was only in her final days, when she needed his help to hold her pen, that he read her words for the first time. Deeply moved by her lifetime's recollections he asked for permission to publish, and she nodded her assent.

Seven years on Joss Ackland, now 81, is delighted that Rosemary's words will reach a wider public. He says: "Working on Rosemary's diary for the past few years has really helped me get through. I am hoping the book will raise awareness of MND and might also help those living with the disease."

"My Better Half and Me" interweaves commentary to tell the poignant story of one woman's incredible life and the couple's living relationship.

The book charts her journey from a teenager in colonial Malawi to her early years as an actress in London. In 1951, and already engaged to someone else, she met Joss when they were both cast in a production of JM Barrie's *Mary Rose*. They quickly fell in love, married and started a family. Yet as two struggling actors they were often on the breadline. Always displaying resourcefulness and immense willpower Rosemary even survived a house fire during which, five months pregnant, she was forced

to battle through the flames to save her children and then broke her back jumping to safety from a bedroom window. After eighteen months in hospital she was the first person ever to walk out after suffering her particular injuries.

As Joss' acting career took off their life became a whirlwind of trips across the globe. But they still remained and exceptionally close family and their lives were shaped by their seven children, from the tragic, untimely death of their eldest son to the births of their numerous grandchildren, who now number 32. Rosemary was diagnosed with MND in 2000 but still continued to accompany Joss on location for as long as she could. Latterly she took up painting, producing some 300 watercolours and crayon drawings. As Rosemary's health began to deteriorate, her diary became a channel to air her fears and frustrations, her resolve to keep fighting MND and her unwavering love for her husband. To the end, her candid, intimate accounts document a wonderful partnership and a remarkable life.

*(Extract from Summer 2009 edition of Thumb Print, MND UK magazine).*

*When we are no longer able to change a situation  
We are challenged to change ourselves  
~ Victor Franklin ~  
(Mouth & Foot Painters' 2009 Calendar)*

## RESEARCH

*The following research articles appeared in the Summer 2009 issue of "Thumb Print", the Magazine of the MND Association, UK:*

### **Protective gene increases survival**

A gene that significantly influences the survival rate of people living with MND has been identified by scientists in an international research collaboration – funded in part by the MND Association.

As well as identifying genetic causes of MND, genetic technologies can be used to find variations that alter progression of the disease. It is this latter approach that has identified a 'protective' gene that extends the life of people diagnosed with MND – the first in the history of MND research.

People with two beneficial variants in the KIF3 gene lived for four years while those with only one or no copies of the beneficial variation lived on average for two years and eight months.

This gene variation does not affect the chances of someone developing MND. The results of this research show that people who already have MND may live longer if they have this genetic variation in treatments. Research will focus on exploiting the effect of this gene variation. Unfortunately, there are no tests available to determine whether a person with

MND has the gene variants that improve survival. We're hoping that it will be possible to have a test for this gene variant within the next five years.

Dr Brian Dickie, director of research development, UK, explained: "This is a significant finding, bearing in mind the speed with which MND can progress in patients. Just as there are genetic 'villains' that can cause of predispose people to disease, so there are undoubtedly 'hero' genes that help delay the onset of disease or slow it's progression."

### **International MND gene-hunt announced**

A major gene-hunting initiative in familial MND has been launched by the Heaton-Ellis Trust, the MND Association (UK) and the ALS Association in the United States.

In 20 years of research, only a handful of genes that cause MND have been identified, two of which were discovered in the past year.

These identified genes account for about 25% of all families affected by familial MND and around 7% of all patients with the sporadic form of the disease (people who have no-one else in the family affected by MND). This means that the cause of MND in 90% of cases is still unknown.

### **Identifying familial MND genes:**

Advances in genetic technology mean that researchers can now capture specific DNA fragments and sequence them very rapidly. These technological advances have not only speeded up the process but also created a significant financial saving as MND researchers can now screen thousands of genes for MND-causing mutations simultaneously at a fraction of the cost.

Prof Christopher Shaw, based at King's College London, who is leading the familial MND gene-hunt, says: "Our ultimate aim is to identify all of the genes responsible for the strongly inherited forms of MND. This will allow us to offer comprehensive genetic testing to 'at risk' but healthy family members. We will also be able to rule out familial MND gene mutations in people with sporadic disease, offering reassurance that their relatives are at very low risk. In addition, the discovery of new MND genes will dramatically increase our understanding of what causes motor neurons to degenerate and allow us to more effectively focus our drug discovering efforts."

*"Life is not the way it's supposed to be – it's the way it is.  
The way you deal with it is what makes the difference"*

**We welcome your ideas – THUMBS UP is your voice –  
So if you would like to Contribute to the next issue – Please write to us !**

## HINTS



*Aids for use on crutches, wheelchairs and walkers*

When you need to take something with you and can't carry it yourself, put it in a "CUB" (crutch utility bag) – Velcro attaches to the crutch/aid and is fully detachable. Available from Debbie Roe in Port Elizabeth on 082 887 1464 or check out her website: [www.cubs.co.za](http://www.cubs.co.za) (It has a NAPPI code (502943\*001) so medical aids cover them)

## FAB – Frenchay Alphabet Board

Is suitable for any person who is literate but is unable to speak, which may be due to vocal chord damage, swallowing difficulties, or people with general communication problems, ventilation or speech difficulties. It is also a useful spelling device when trying to talk to people with hearing problems. More details regarding FAB available on [www.fab.uk.com](http://www.fab.uk.com) or [www.e21.uk.com/store](http://www.e21.uk.com/store)

## DISABLED TRAVEL



One of the most beautiful parts of the Free State is the picturesque town of Clarens near Golden Gate. The town's Artist Amble takes you to all the various art and craft shops and fly fishing is available just

outside Clarens. The shopping mall with a restaurant is accessible and there are 3 accessible accommodation venues: Ash River Lodge, Craigrossie Trout Lodges, Protea Hotel Clarens.

For more "travel" info, go to: [www.disabledtravel.co.za](http://www.disabledtravel.co.za)

## Sanparks:

– Kruger National Park have added new units to several camps: Berg-en-Dal; Satara; Lower Sabie

## RECIPES

**Ensure® Oats Porridge**

100ml raw oats  
100ml cold water  
1250ml boiling water  
Pinch of salt

4 scoops Ensure® powder

Mix oats and cold water in a saucepan.

Place on heated hot plate and add 250ml boiling water. Bring to boil stirring continuously.

Turn down heat and simmer until done.

Just before serving stir in Ensure® powder.

If desired, add chopped banana or walnuts.

For extra protein, add 2 scoops of Promod®

**Apple Cake Pudding**

|                          |                      |
|--------------------------|----------------------|
| 30ml margarine or butter | 2 Eggs               |
| 250ml flour              | 250ml sugar          |
| 5ml baking powder        | Pinch of salt        |
| 60ml Ensure® Vanilla     | 1 med tin Pie Apples |

Cream margarine and sugar, add eggs, and beat well. Add all dry ingredients and Ensure® alternately. Mix well. Pour into creased pyrex dish. Arrange Pie Apples on top of mixture. Bake @ 180°C for 45 mins.

*Sauce*

|                       |                     |
|-----------------------|---------------------|
| 190ml Ensure® Vanilla | 60ml sugar          |
| 50ml butter/margarine | 5ml vanilla essence |

Mix together in a saucepan. Stir over gentle heat until butter has melted and sugar has dissolved.

Pour over pudding as soon as it comes out of the oven.

Serve with Ensure® custard.

**Ensure® Jelly**

250 ml Ensure® Strawberry

10ml gelatine

20ml warm water

Dissolve gelatine in warm water.

Mix into Ensure®. Pour into bowl and refrigerate until set.

**Strawberry Milkshake**

250ml Ensure® Strawberry

100ml vanilla ice cream

Place ingredients into blender and blend until smooth. Serve immediately.

For extra protein, add 2 scoops of Promod®

**Ensure® Custard**

250ml Ensure® Vanilla  
 30ml custard powder  
 30ml water  
 Heat Ensure® in a saucepan on stove.  
 Mix custard powder with water to form a paste. Add hot Ensure® to mixture stirring well.  
 Return to stove on a low heat and stir continuously until it thickens.

**Ensure® Chocca-Mocca**

250ml Ensure® Chocolate (mixed)  
 5ml coffee powder  
 Warm Ensure® in a mug in microwave for 1 to 2 minutes on high, or warm on stove.  
 Add coffee and stir.

**Condolences** to the family and friends of:  
 Stephen Goodwin, George Mahambie, Colin Dainin, Philip Riphagen, Roy Rentzke, Chris Small, Yda Moodley, Disree Rust, Alec Roelf, June Long, Cornelia Baker, Prof Andy Gilbert, Wilma Louw, Stephanie Torr , Martin Schneider, Catherine Mercy, Ian Billingham, Benjamin Motshgwa, Billy Owens

***HELPING THROUGH YOUR WILL***

*Your Will can be a convenient vehicle for making a charitable gift of a lasting value. Please consider MND Association as a living memorial for a loved one. Many people support the work of the MND Association of South Africa through bequests from their Estates.*



*The gang usually is comprised of four members: 1 adult, and 3 younger ones. While the three younger ones, all appearing sweet and innocent, divert their victim with a show of friendliness, the fourth, (the eldest), sneaks in from behind the person's back to expertly rifle through his or her pockets and purses or bags for any valuables being carried. (This is the gang in operation !)*

**MOTOR NEURONE DISEASE ASSOCIATION of South Africa**

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