

Thumbs UP

MND / ALS
ASSOCIATION OF SOUTH AFRICA 

The Newsletter of the
Motor Neurone Disease /
Amyotrophic Lateral Sclerosis
Association of South Africa

May/June 2014



**One #GlobalTeam
One Goal**

A world free from ALS/MND
ALS/MND Global Day, 21 June 2014

*People who care make
a world
of
difference*



**International Alliance of
ALS/MND Associations**

*United in the worldwide fight
against ALS/MND*

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.”

MNDA of South Africa is a member of the International Alliance

PATRON	NATIONAL CHAIRPERSON	VICE CHAIRPERSON
Aviva Pelham (M. Mus.)	Dr. Franco Henning	Sheila Kendal
SECRETARY		
Rina Myburgh		

ACKNOWLEDGEMENTS

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*How is it that one careless match can start a forest fire
but it takes a whole box to start a campfire ?*

Whether we start a forest fire or a campfire : we can fan the flame of Awareness !

21 June is ALS/MND Global Awareness Day

“People who care make a world of difference”

Global Awareness Day in Gauteng : Barnyard Theatre, Rivonia

“Thank you for the Music”

an ABBA, Queen and The Bee Gees Production

(The glitz, glam and greatest pop tunes of the 70’s and 80’s)

Tickets @ R160 available from Kevin Jordan (**YOU & ME VERSUS MND**) 082 608 0661

or Liz Keth 082 878 3716

AWARENESS IN ITALY

The following e-mail was received from Massimo Mauro, the National President of Aisla Onlus, (the Italian Association Amyotrophic Lateral Sclerosis):

“We want to share with you the new video manifesto of ALS Italian non-profit organization carried out for Aisla by 4 young students that won Spot School Award 2013, festival for young creative talent.

“Our spot “This is a story” (<https://www.youtube.com/watch?v=FLJz9OCec0>) has been adopted by Aisla, which has been working for 31 years in support of ALS patients, as a video and poster tool in order to raise awareness over the disease: the creativity of young people revealed to be mature.

“Since years long gone by the first Public Information, communication has learned to concentrate and bring to fruition strategic, creative and productive efforts. Advertising, the old and cynical soul of commerce, has always agreed to get involved. More unusual, however, is the fact that it is not selected creativity of an agency but that of young students.

“The spot deals with a young girl, Francesca. Her story is told through images of her diary where the protagonist speaks of her life (boys, friends), of her passions (travels, Vasco Rossi’s music), until the appearance of the first symptoms of ALS (Amyotrophic Lateral Sclerosis), the diagnosis and the will to live, despite the fear.

“The spot-manifesto of patients with ALS was born from a video shot through a smartphone by four students of the University of Rome (Chiara Simmi, Lavinia Barbarossa, Michela Cianciullo, Athena Marcucci). In order to conceive the story of Francesca the authors were inspired by the stories of patients with ALS (about 5,000 in Italy). Among them young women who are fighting against the disease. Among the many valuable contributions and interest, the long video “This is a story” was selected and awarded by a panel of qualified experts (Project manager Gerardo Sicili with creative direction of Isabella Bernardi, a production company with Nantucket direction, photography and installation of Alessandro Soetje). The WE-B of the digital agency Aldo Biasi Communication will eventually manage to tell this nice story to the network, the story of this book that asks the world for help to turn the page.

“Let us share the deep emotion raised by this video with all of you.”

*Someday everything will make perfect sense
So for now, laugh at the confusion, smile through the tears
And keep reminding yourself that everything happens for a reason !*

Kasturi Pillay, our Support Group Co-ordinator in the KZN area, tells us about the
MNSA FUNDRAISING DANCE
Organized by her for 27 April 2014

"I was advised by Mrs Jessica Solomon, an occupational therapist in Durban, that there is a device available to help MND patients communicate with family and friends in the latter stages of life. Jessica Solomon is currently counselling and helping one of my MND patients, Jasmine Moodley.

I was motivated to co-ordinate this Fundraising event. The reason being, I fully understand what it is like to live with someone who has MND, I have cared, seen and lived through all the phases of this horrible disease and from that I can say that I have become stronger as a person and nothing is too big to make a difference in someone's life.

I mentioned this device to some of my close friends and family on 25 March 2014. Everyone was in favour of trying to acquire sponsorships and a method of trying to raise funds to purchase this device for use by Jasmine Moodley. The intention was to currently purchase this device for Jasmine and in the future, it will be loaned to other patients in the Durban and surrounding areas, for their use.

My small committee of ballroom dancing friends decided that we should organise a dance in order to raise funds. The hall was booked the very next day and we scheduled the function for the **Sunday, 27 April 2014. The venue was New West Secondary School hall in Newlands, Durban.** The price of the ticket was set at R100-00 per person.



The MND/ALS Association's mission 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.

Cape Town
 Tel: 021 531 6130
 Fax: 021 531 6131

Email: mndaofsa@global.co.za

Website: www.mnda.org.za

**(Affiliated to the Hospice Association)
 (NPO No 003-462)**

Kasturi Pillay (Durban MND Support Group Co-ordinator) delivering her welcoming talk at the Fundraiser held on 27 April 2014

The tickets were sponsored and ticket sales started the very next week. In the interim we had a local radio station broadcast our function on a daily basis. Due to word of mouth many people also advertised our function to other dance schools, friends and family.

This function was a tremendous success and we raised an amount of R30 000-00. This amount was due to ticket sales, generous donations, raffles and sponsorships. The only expense incurred was an amount of R1200-00 for the live band. I also gave away 10 gifts as lucky draws, which were sponsored.

The format of the function was as follows :

- Bring your own meals and drinks.
- To open the function, we observed a few minutes of silence for all those people that have passed on due to MND.
- Thereafter I officially welcomed all the guests on behalf of MNDA. I gave an outline of what MND is all about and the difficulties. I also made them aware of what kinds of comfort treatment MND sufferers can experience in order to make their lives a bit comfortable. I also made the congregation aware of the different stages of an MND patient.

A Quote from my speech: “It is a horrible condition that leaves people trapped in a physically disabled body but the saddest part of it all is that their highly active and intelligent minds are confined in their bodies : Ladies and Gentlemen, please take a moment to imagine having a mind that is passionate to live life, but physically not being able to, no voice to convey it to the world, it is the saddest thing MND patients are faced with”. I also mentioned this device would be of great use to a woman who is still vividly enthusiastic to live Life to the fullest.

- Jessica Solomon was called upon to give a detailed explanation of the function of the ACC device.
- A slide show was screened so that people would be aware of what kind of support, outings, fundraising events and meetings, patients are involved in.
- While people were involved in dancing, raffle sheets were circulated at R10 per line. I had made 200 numbers for the raffle. To my amazement, all the raffles were taken within 30 minutes. The guests donated generously.
- Midway through the function, the lucky ticket draw and the raffle prizes were done.

One of the professional dancers conducted a line dance for all the guests to participate in, including the people that don't do ballroom dancing. This was a captivating experience for all that attended.

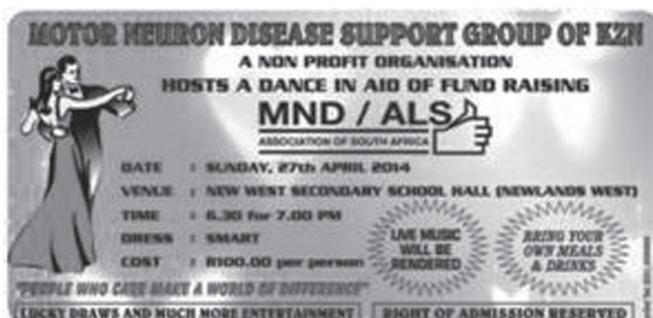
Some of the prizes that were sponsored and donated for the lucky ticket draw and raffle draws were :

- A holiday for six people anywhere in South Africa – by Club Leisure Group
- A car DVD player with LCD monitor – I donated
- Two bottles of expensive wine – my friends
- An electric carving knife -friends
- A portable radio- Sevela my friend
- Four hair and manicure vouchers - Cheryl
- A flask set – Jenny and Neil

In conclusion, I was absolutely impressed with the outcome of this function and the generosity of people in supporting our fundraiser. A special thanks to my friends that helped me in organizing this event. I could never have done this function without their assistance. I am in the process of sending letters of appreciation to all my donors and sponsors.”

Kasturi Pillay

The MND Association of SA is extremely grateful and appreciative of Kasturi's efforts and would also like to thank everyone who participated and contributed to this event to make it the success it was.





MND Fundraiser April 2014

Guests enjoying the evening

~~~~~

*I might not be someone's first choice, but I'm a great choice  
 I may not be rich but I am valuable  
 I don't pretend to be someone I'm not, because I'm good at being me  
 I might not be proud of some of the things I've done in the past  
 But I'm proud of who I am today  
 I may not be perfect but I don't need to be  
 Take me as I am, or watch me as I walk away.*

**DONATIONS**

A big thank you for the "extra little bits" added to some of the membership fee payments, ie the bits more than the R200 ! We also thank everyone who so kindly supports us monthly, annually or periodically, and those who make a donation to MNDA in lieu of gifts to friends and family.

And on special occasions: Patient Basil Sheasby and his wife Deanne, recently celebrated their 50th Wedding Anniversary and requested their family and friends to donate to MNDA rather than buy gifts - thank you so much for that very kind gesture.

***THE FOLLOWING PARAGRAPHS MAY BE DISTURBING TO OUR READERS,  
BUT IT IS SOMETHING THAT CONCERNS US ALL:***

*Excerpt from the Winter 2014 issue of “Thumb Print”, magazine of the MND Association, UK:*

*Candid information about End of Life*

People have shared their views on end of life issues through recent surveys and studies which are now helping to provide information, shape future research and campaign on this important and sensitive area. People often find it difficult to discuss the end of life with those close to them and with health and social care professionals. However, these conversations can also worry professionals. It is not an easy subject, but the “unknown” causes most fear.

People with MND who do wish to discuss end of life planning, are seeking full, clear and honest answers. End of life decisions involve a wide range of subjects from treatments to personal finances and planning for the family’s needs. As a result of feedback, a publication called ***End of Life – a guide for people with motor neurone disease*** has been developed. A range of issues is covered in a candid and comprehensive way, including how the disease will progress, the treatment and withdrawal options available, how to talk about these and how to help ensure your decisions are respected.

With MND it is particularly important to have discussions about end of life as early as someone feels ready to do so. Speech and communication can be affected, which may make discussion increasingly difficult. Some people also experience changes to the way they think and reason, which may impact on the ability to make decisions. Yet, having made their decisions, many people say they feel relieved. They can then put them to one side and get on with living.

Dr David Oliver, Consultant in Palliative Care Medicine, Wisdom Hospice, Rochester and Honorary Reader, Centre for Professional Practice, University of Kent, (and also visited MNDA in South Africa a few years ago) acted as a mentor throughout the development of the guide. He said: This publication will encourage end of life discussions between people with MND and their family, and with health and social care professionals. They may be difficult conversations, but they are so important, as they allow the person with MND and their family to ensure that their own wishes are known and that appropriate care and support can be provided.”

*(MNDA of SA made enquiries about obtaining a copy of this guide and have been advised that our name is on their mailing list for when the publication becomes available)*

Death is unavoidable for every human being and is a natural sequel to life and “The Living Will” is something which we should all consider. A very simple copy (free of charge) is available from the MNDA office

OR

You may consider SAVES – The Living Will Society (see back page) [Pamphlet also available in Afrikaans.]



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

***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.*

**MOTOR NEURONE DISEASE / ALS ASSOCIATION OF SA**

|                                                                                                                                     |                               |                                           |                                  |
|-------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|-------------------------------------------|----------------------------------|
| Cape Town Office<br>P.O.Box 789, HOWARD PLACE, 7450,<br>TEL: (021) 531-6130<br>FAX: (021) 531-6131<br>E-mail: mndaofsa@global.co.za | Gauteng<br>CELL: 082-878-3716 | Port Elizabeth Area<br>CELL: 079-591-2148 | Durban/KZN<br>CELL: 083-777-2029 |
|-------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|-------------------------------------------|----------------------------------|

An article featured in a recent issue of the “Tatler” (a Cape Town Community Newspaper) reports about the functions of Hospice, and in this particular case, St Luke’s Hospice in Kenilworth, Cape, caring for patients suffering from life threatening illnesses, but a growing misconception of what the hospice is all about has not helped its cause.

Their Chief Executive Officer, Priscilla Nelson, said we are still living in a death-denying society and members of the public still associate Hospices just with death and dying. Hospice are striving towards helping people to live their lives to its fullest until they die. Many patients are referred to hospice a few days before they die, which is not ideal as the hospice is unable to achieve much at such a late stage. Hospice provides care to the total person, which includes psycho-social and spiritual care as well as pain and symptom control. Their unit of care is the family, not just the patient. St Luke’s Hospice comprises a professional group of staff members, including medical staff, professional nurses, social workers and spiritual carers, who also look after patients in the comfort of their own homes. Through hospice care, they strive towards getting the patient and the family members to sort out any outstanding issues such as making peace with one another, asking for forgiveness, etc. to get them to a point of dying a good death. They also run a bereavement service for the family after the patient’s death.



### From the April issue of “Alzheimer’s South Africa’s Memory Magazine”:

Cats and dogs are proven four-legged stress busters.

People feel less anxious when Pumpkin or Shadow is around and their blood pressure reflects their calmer state of mind, according to a series of studies by Karen Allen, PhD, psychology professor at the University of Buffalo in New York. “Pets have a calming effect and can help lower responses to everyday stress, even situations over which we have no control”, says Dr Allen. “They provide unconditional love – and they’re always on your side”.



### Condolences to the family and friends of:

Gerhard Strauss (21/1), Shipo Pqphanga (28/2), Tony Unger (6/3), Manie Lee (12/3), Mr Gouws (12/3), Louw Brink (19/3), Gerhard Jonas (25/3), Hoosen Khan (29/3), Dinah Mtungata (No details), Michael Booysen (13/4), Rosa Barnard (16/4), Mavis Mumford (18/4), Renier Gertenbach (21/4), Danie van der Merwe (21/4), Sarah Fick (26/4), Peter Isaacs (15/5), Elsa Gravett (21/5), Esther van Zyl (23/5)

HAVE  
YOU  
SIGNED  
THE  
LIVING  
WILL?

## *The Living Will...*

SAVES *S*uffering and pain

SAVES *A*nxiety for loved ones

SAVES *V*alueless prolongation of terminal illness

SAVES *E*xistence without quality of life

SAVES *S*pending life savings unnecessarily

## **SAVES – The Living Will Society**

**SAVES - The Living Will Society** was formed in KwaZulu-Natal in 1974 and over 50000 people throughout South Africa have become members and signed Living Wills. The Society bases its operation on the following principles:

1. That death is inevitable for every human being. It is a natural consequence of life and ought to be as dignified and humane as possible.
2. That in the event of terminal illness, or where there is no imminent or reasonable chance of recovery, the employment of artificial means to sustain life is pointless and only serves to prolong unnecessarily the distress of all concerned.
3. That in such cases a humane and acceptable alternative should be sought, in the form of a declaration setting forth one's instructions. Allowing death to occur naturally, through the withholding or withdrawal of artificial life-support systems which would otherwise sustain "Life" – but one of little or no quality, is known as passive euthanasia and is accepted by major religions worldwide. (Active euthanasia – so called "mercy-killing" or physician-assisted-suicide – does not receive the support of the Society.)
4. That every effort should be made to relieve the patient from any mental or physical pain and discomfort, even if medication administered exclusively for this purpose hastens the moment of death.
5. That any life-support systems such as ventilators, respirators or other sophisticated and possibly costly medical techniques be used prudently to sustain life where there is a reasonable chance of recovery; not merely to postpone the moment of death.
6. That a mentally competent adult patient has the legal right to refuse medical treatment should he/she so wish, and in such instance the doctor is legally obliged to honour the patient's wishes.

## **The Living Will**

To this end, a document called '*The Living Will*' was devised to stand as a testament to one's wishes, particularly in the event of one being unable to communicate when one is dying.

The Living Will is addressed to your family and physician, and states:

*"If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive."*

*"If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I do not give my consent to having my dying process prolonged by artificial means, including any pacemaker, nor do I give my consent to any form of tube-feeding when I am dying; and I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress even if the moment of death is hastened."*

Three (or more) original Living Wills should be signed when of sound mind and after careful consideration, in the presence of two witnesses. It is imperative to share this decision with anyone who may have to implement the Living Will i.e. Your doctor/s, family and friends who must be told where you keep your Living Will.

We suggest that these documents be lodged in the following manner:

1. Kept at home in a safe place for easy access by family/friends.
2. Lodged with your doctor, after full discussion of the contents, so that in advance of the possible need, the doctor understands your wishes. Should there be no private doctor, arrangements can be made to have this copy filed in your out-patient file at any hospital.
3. Kept for inclusion in your in-patient file should the need for hospital, nursing home or hospice arise.

**N.B.:** Residents of Retirement Complexes/Old Age Homes should apply for an extra copy of the Living Will to be left with either the Management or the Clinic Sister.

Members are supplied with a Wallet Card, which draws attention to the fact that they have signed a Living Will, and advises where their Living Will can be found in an emergency.

## How to Obtain The Living Will

Any person above the age of 18 years and of sound mind may join **SAVES - The Living Will Society**, regardless of race or creed. A woman married in Community of Property does not need her husband's authority when signing a Living Will.

Upon the Society's receipt of your fee and completed enrolment form (see over), you will receive three Living Wills, a Wallet Card and Stickers, together with instructions regarding the signing and lodging of each document.

As a registered member your non-consent to artificial life-support when dying will receive the back-up of the Society. An annual Newsletter will keep you informed of the progress of this and similar organisations worldwide.

The Society is a non-profit organisation and donations are always gratefully accepted to assist our work.

## Enrolment Form

To: The Director Date: .....

### SAVES - The Living Will Society

P.O. Box 1460,

WANDSBECK 3631

Phone: (031) 266-8511

Fax: (031) 267-2218

E-mail: livingwill@3i.co.za

www.livingwill.co.za

Please enrol me/us as a member/s of the Society and forward my/our Living Wills, Wallet Card/s and Stickers.

I/We enclose my/our membership fee:

- R 80,00 per person (including Pensioners)
- R 150,00 per married couple (including Pensioners)
- R 30,00 per person receiving a Government Old Age Pension, or Disability Grant.

PLEASE PRINT

Surname: .....

First Names (Mr): .....

First Names (Mrs / Ms): .....

Postal Address: .....

.....

..... Post code: .....

Residential Address: .....

.....

..... Post code: .....

Tel: (.....) .....

e-mail: .....

**ANNUAL SUBSCRIPTIONS** fall due on member's receipt of the Annual Newsletter: R30 per person (including pensioners) or R10 per person receiving a Government Old Age Pension or Disability Grant.

**CHEQUES, POSTAL ORDERS OR DEPOSITS** to be made payable to **SAVES-The Living Will Society**

**DIRECT DEPOSITS:** Standard Bank (Westville Branch Code No. 04 54 26), Current Account No. 05 307 4416. Please give your **FULL NAME** and Fax or Post the deposit slip to us with your completed enrolment form.

**Electronic:** Please give **FULL** details (as required on the enrolment form) and furnish proof of payment therewith.

## ADVANCE DIRECTIVE

### To my Family and my Physician

This declaration is made by me .....

at a time when I am of sound mind and after careful consideration.

If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.

If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I do not give consent to be kept alive by artificial means, and I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress even if the moment of death is hastened.

I hereby consent and authorise my spouse, children, partner or any member of my family to apply to the Supreme Court for a Court Order to compel compliance of this directive should any medical practitioner or hospital refuse to give effect to the said directive.

This declaration is signed and dated by me in the presence of the undermentioned witnesses.

SIGNED .....

DATE .....

Witnessed by:

SIGNATURE .....

DATE .....

Name .....

Address .....

SIGNATURE .....

Name .....

Address .....