

Thumbs UP



The Newsletter of the Motor Neurone Disease Association of South Africa



Kevin du Preez (left) Organiser, with Liz Keth our Consultant in Gauteng, patient Gert Theron (3rd from left) and other members of Club 32, at the Golf Day presentation

**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

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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

Kargo National for transporting our equipment.

FROM THE OFFICE

Our previous Secretary, Vivienne Zilberg, who served the Association with dedication and loyalty for +12 years, and herself a MND patient, passed away on 21 August 2006. This issue is dedicated to Vivienne and her story appears elsewhere herein.

With time marching on, Christmas is fast approaching which means it is Christmas Card time. We attach our order form and appeal to you for your support in ordering/buying our cards as this is one of our main fundraisers and we certainly need those funds !

We remind you that we do not receive any state funding and depend entirely on donations, bequests and our own efforts at fundraising, to generate income.

Please put your heads together and think of some small ways you can help us to raise funds.

PLEASE SUPPORT US.

NEWS

We are very grateful for the Donations received from:

The Philip Shock Trust, SW Kirsten, WR Terry, Dr S Hellig, Ackerman Family Trust,

In memory of Walter Gaiser, SL MacFarlane, DE Long, LD Maule, JJ Coetzer, J Gaiser, JW Jewell, JA Milner, F Potgieter, KB van Zyl, J Kelly, M Botma, F Serfontein, S van Blerk, GE Knight, J Kruger, AL Steyn, S Cole-Willey, J Zaal, I Naik, R Stander, S van Zyl, VM Pepler, C Jordens, MD Kelly, D Cuthbert, Family of Dr GM Mosam, N Watermeyer, P Halstead, Des Munroe, MG Norman, JC Wood & D Clack, Al Gove.

When patient **Charles Levitt and his wife Shirley** of Sea Point (Western Cape) recently celebrated their Golden Wedding Anniversary they requested their family and friends to send their "gifts" in the form of donations to the Association.

We thank:

Aubrey & Hazel Berman and family, Ruth Stander, Benny Miller & family, Mokie & Necia Miller, Stanley & Janice Bloch, Brian & Karin Zolty, Matty & Ruben Goodman, Pat & Cecil Herman, David & Arlene Bloch, Vera & Nick Angel, Prof Margaret Hofman.

Ruth Jowell celebrated her 70th birthday and she too very generously requested her family and friends to donate their "gifts" to our Association.

We thank:

WM Friedman, Prof Norma Saxe, Esther Rabinowitz, Mrs M Jacobson, Shirley Steiner, Esther Seidel, Prof Margaret Hofman

And

Many thanks for the "extras" received with membership fees. It is so very much appreciated.

Gert Theron, a patient from Edenvale is a member of "Club 32" at Royal Johannesburg Golf Club. They held a Golf Day on 8 August and the MND Association of SA was one of the nominated beneficiaries of the day. We are very fortunate and

extremely grateful for the R15.000 donation received. Thanks go to each and every person who participated, the players, the sponsors and especially Kevin du Preez who did all the organising. Well done !

This is what Gert had to say to his fellow members of Club 32 at the presentation:

I want to thank you all for this donation – thanks to everybody that contributed your time and/or money to this Association. The support that people like my family and I received from the Motor Neurone Disease Association is something that I cannot describe to people unless you need specialised advice and help. Thank you for a group of friends like you.

We thank them all for their kind gesture and generous support.



Gert and his wife Rennie thanking his fellow members of Club 32

Fundraising

The MND Association is fortunate to have been selected by the Union of Jewish Women (Constantia) to share the proceeds of the show "**The King and I**" which is being staged at **The Artscape Theatre on 11 October 2006**. Tickets at R85 each are obtainable from Roxy on 082 468 8980.

PLEASE SUPPORT THIS EVENT !!

Jacques Rossouw, wrote on 12 July, about "Life in Wilderness"

Thank you for the latest Newsletter. Like all the previous ones, this was again read with great interest.

Wilderness, one of the most beautiful destinations in our country, is only 15 Kms away from George and is known as the Capital of the Southern Cape and Garden Route.

Myself and Joseph, my friend and companion for 28 years, moved to Wilderness from Kommetjie near Cape Town to retire in "The Garden of Eden" towards the end of 2002. Both of us had been working very hard, were successful businessmen and were now looking forward to do the things that we never had time for or did not allow us to do.

We would have walked all the trails in and around Wilderness, spend time fishing, taking up bowling and explore our beautiful Country and go abroad to foreign countries we have not been to before. Those were the wonderful dreams we had for our "Silver Age".

Shortly after our arrival in Wilderness, I noticed that my left leg was not functioning normally. I thought it was only a temporary condition and possibly the after effects of quite a few back operations. There were many doctors, neurologists, more operations, trips to Cape Town and back and during the last operation a "plate" was inserted in my neck. My leg became worse. More neurologists and eventually towards the end of August 2005, had I been diagnosed with MND.

MND was unknown to us. The neurologist gave me three months to live. I have made peace with my condition and daily thank the Lord for a wonderful companion/carer who still believes in our dreams of nearly four years ago before we moved to Wilderness. Live life, it is not a rehearsal.

Maggie Badenhorst of Newton Park, PE, writes:

As a family, we would like to thank the Association for sending us, on a regular basis, Newsletters and advice. I would like to express our gratitude and appreciation for the support and encouragement which we received from St Francis Hospice and special thanks to Sr le Roux from Port Elizabeth. My husband Paul Badenhorst was diagnosed three years ago with Motor Neurone Disease. He passed away peacefully on 27 June 2006, after a brave struggle. During this difficult time in my life, we were fortunate to have received invaluable support, visits, advice and various items of equipment that helped us cope, as my husband's condition was deteriorating. Thank you Hospice for all your help.

God bless you all for the wonderful work you are doing, and all the families affected by Motor Neurone Disease.

Arthur Christie of Highlands North, whose wife Margaret has MND, tells us of a recent (pleasant!) experience:

My wife suffers from MND. Fortunately we are still able to get out to restaurants and the theatre, albeit in a wheelchair.

On our recent visit to the Johannesburg Civic Theatre, we were most impressed by the trouble they took over our booking, parking facility arrangements and escorting us to our seating section. A copy of my letter to the Manager is enclosed. (And reads as follows:)

My wife is confined to a wheelchair and I would like to compliment your staff on the efficient and courteous way they handled the ticket booking and arranged for disabled parking facilities when we attended a performance of "We Will Rock You" on Sunday 25 June at 2pm.

When we arrived at the theatre, we were directed to our parking bay, and once inside the building, efficiently escorted to our seats.

Our enjoyment of the show was in a large part due to the way your staff handled all the arrangements.

Congratulations to your staff.

(It is pleasing to note that the staff (at the theatre) went that extra mile to make Arthur and Margaret's outing as pleasant as it was and we are sure they in turn appreciated Arthur's letter of thanks!)

Jean Gaiser of Umhlanga Rocks, whose husband Walter passed away in May 2006, writes :

Firstly my sincere thanks and appreciation to the MND Society for all the hard work and support that you give tirelessly to our community in assisting the patients and families having to deal with MND.

In honour of my husband, Walter Gaiser, who lost the battle to MND on 24 May 2006, I am going to stay on the membership role of the MND Association.

After reading the June newsletter tonight, I have decided that it is really important for me to write a short article for the next newsletter, firstly in honour of my beautiful and precious husband, who was truly one of life's "gentle men" who lost the battle to MND on 24 May, and secondly because we have tried so many of the "alternative treatments" I feel very strongly that other people really need to know about the various things that are written about / advertised promising the "miracle cure" before going headlong in to things without doing an absolute and complete check on the various products and the companies that promote them before they spend lots of money that could possibly be far more beneficially used with therapies that do work or at least bring some relief for the patient, besides the emotional roller coaster one goes on when things do not bring the promised / required results.

(We look forward to Jean's contribution in memory of her husband).

Vivienne's story – in her own words:

I, Vivienne Angela Halstead was born on the 21st Nov 1938 in Nuneaton, Warwickshire, England to Vera and Geoffrey.

War broke out the following year so my father being a chemist

and unfit for military service continued running his chemist shop in the High street of Hinckley. He manufactured his own remedies and tablets. My mother made babies' waterproofs and cosmetic bags on her sewing machine as none of these things were available. I went to the local convent. My brother Roger was born in Jan 1943 followed by sister Bunty in September 1944.

Afer the war, the winter 1947/48 was the coldest in living memory and my pony used to come up for bran mash in the morning with snow on her back. My father built us a large sledge so that all the family could toboggan down the hill together. He also made a smaller flat one for me so that I could go down on my tummy. It really was a very exciting time.

My parents decided to emigrate to SA and we sailed on the Caernarvon Castle from Southampton in July 1948. This ship was still a troop ship configuration with three tiers of metal bunks. Men were on E deck. Women and children were separate on A deck. This was a real adventure. I collected stamps and got friendly with the purser who had a magnificent collection. He took me under his wing as I was nearly 10 and very interested in the workings of a ship, he even took me inside the funnel. Nobody would believe me.

My parents had brought a large caravan which was trans shipped onto another ship, the Cape Town Castle to Port Elizabeth, where we landed and set up a caravan sales site in the bush. This was my mothers first experience of wild bush and snakes. I went to the local convent with my brother Roger, St Dominics Priory as a boarder.

In 1949 we moved to Johannesburg and I was sent to St Ursula's convent in Krugersdorp as a boarder as my folks lived in the caravan and sold caravans in order to make a living. My father used to do locum work at the chemist in Orange Grove on holidays and weekends in order to augment the family income.

In 1950 we moved to Rivonia and I was sent to Barnarto Park, Johannesburg High School for Girls as a day scholar. My parents had bought a small holding with river frontage, a dilapidated cottage, a well and many fruit trees. My father renovated the cottage and this was on 12th Ave, Rivonia. There were no roads in those days. It was a dirt track that eventually with use became a dirt road.

My pony used to graze all day and come back and wait at the gate in the evening. We had to close the gate as the neighbours' cows ate the veggie patch. There was one bus per day in either direction to or from Johannesburg. The total population in Rivonia was probably 500 people at this time. There were two churches, the Carmelite convent and the Apolstolic

Church. We used to walk to visit our friends and we never locked a door. Life was very secure and pleasant. The local police station was run by Sgt "Blackie" Swart from an old house on the corner of 12th Ave and the Main Road. There was a mounted police service with stables in Sandown and they used to patrol as far as Rivonia.

I left school at the end of 1954, did a 6 month secretarial course and started work as a junior shorthand typist in Sept 1955 for the Gramophone Record Company, (a subsidiary of Gallo). This was an exciting job. I was responsible for the sample library of records of artists like Frank Sinatra, Johnny Mathis and Miriam Makeba who had just recorded her first album on the Tropik label.

In 1958 my mother and I went to England to see the grandparents. It had been 10 years since she saw them. We flew by Trek Airways in a DC 4 Skymaster. It took 4 days, we left from Jan Smuts, stopped in Livingstone to refuel and then to Entebbe where we slept the night in Kampala. The following day we flew to Wadi Halfa in the Sudan to refuel and then up along the Nile to Cairo where we spent the night in the Heliopolis Palace Hotel. This had recently been vacated by King Farouk.

We did the usual tourist thing and saw the Sphinx by moonlight and decided that camels must be the smelliest things on earth. The following day we flew across the Mediterranean to Nice which is a short haul flight so we had time in Nice. We went out to a restuarant and a strip show in the evening. My mother and I had never seen anything like it before.

The following day we flew to Paris, Le Bourget Airport where we took a smaller aircraft to London as not all passengers were for the same destinations.

We visited Grandmother Smith at 24 Cavendish Ave, Eastbourne and Granny and Grandpa in Hythe, Kent. Vera flew back after a month but I decided to stay and worked in London as a shorthand typist and waitress until Nov 1959. During my time in London I lived on a houseboat on the Thames underneath Battersea Bridge, the address being Cheyne Walk. There were 35 converted wartime landing craft moored against the embankment. All of them were occupied by young people like ourselves. I made some very good friends. Anyone too drunk fell over board into the dirty Thames mud. The Thames River Police paid us regular visits.

I returned on the Caernarvon Castle for my 21st birthday. The ship had been refitted as a passenger liner. I then took the train to Johannesburg and immediately looked for a job. I got a temp 3 week position at UAT French Airlines but was asked to stay on which I did and worked for them for many years.

They merged with TAI and the airline became known as UTA French Airlines. This was still a private company.

I married Peter van Niekerk on the the 17th January 1965. I had two children, Nicola in 1965 and Michael in 1968 in between working. We moved to Pretoria in 1967 and I worked for the UTA Pretoria office until 1973. During this time we moved to Halfway House where we started the Hatherley Hunt Club with 8 pairs of hounds. We rode horses, hunted and enjoyed the country life. I got divorced from Peter in 1973.

I went back to work for Sabena on a casual basis at the airport. I also sold Tupperware and AMC pots. In January 1981 I joined the staff of Sabena Johannesburg as a Sales Rep and bumped into Benjamin Zilberg whom I and my family had known for many years. We were married on the 15th Dec 1982 and I continued working for Sabena. In 1986 Ben and I had a very traumatic financial upheaval. I was then running the Sabena Pretoria office. In the course of my job one day I ascended a flight of stairs from a travel agency to find that my body had frozen and I could not move at all. I was like a statue. It seemed like a long time but was probably seconds but I managed to get to a bench where I sat for a few minutes. During this time I was suffering from severe cramps in my legs at night and pins and needles in my arms which nothing would alleviate. I thought that it was old age or mid life crisis and maybe I should take life easier.

However we then had an offer to run and renovate a derelict wine farm in Franshhoek as Benjamin was a qualified accountant and architect we accepted the offer. While we were there on several occasions I found myself sitting on the ground. Once I ran up the steps to find myself scraping my shins on the bricks for no reason at all. I did not trip. My right foot started to drag and I said to the local doctor that there was something wrong with my leg but he could find nothing wrong.

We left the beautiful valley of Franshhoek to go to Citrusdal to manage the Cedarberg Hotel. My right foot got worse and the astute lady doctor agreed that something was amiss and sent me for a full physical. The physician found only one thing wrong, my reaction to his hammer on my right ankle. He took a full spectrum of blood tests. When he received the results he sent me to Neurology at Groote Schuur as there was an imbalance of glutamate. I went to Groote Schuur and spent 4 hours having tests under the guidance of Professor Eastman. While the doctors were huddled in a corner I said to Professor Eastman that he must not feel embarrassed or reticent to give me the diagnosis as I knew I had MND. My paternal uncle John had died of MND in 1989 after only 2 ? years since diagnosis. As there is no known cause or cure I accepted the fact that there was nothing I could do other than enjoy every day

that I had left. I was 50 years old and I had had a very adventurous life so I did not feel as traumatised as most people do when they are diagnosed.

Ben and I then moved to Sea Point to 401 Lido Court. We drove an automatic car at this stage. In 1992 I made enquiries about an MND Association and was told by the British Association that the only one in Africa was in Cape Town. I contacted them and met Christine Swanepoel, Diane Heron, Elsabe Burger and Vivien O Cuinnegain. I offered to take the minutes of their meeting and the result was that I became the secretary and we started a newsletter. At this stage I could still walk with a stick and had grab handles installed in the house. I could still cook sitting on a hairdressing stool.

My husband Benjamin died suddenly in February 1996. I was obliged to move and as my mother was widowed we decided to live together in Pinewood Village, Pinelands, Cape Town. I converted the garage into an office with the MND equipment and office furniture and we ran it from there until I was no longer able to type. Then Rina Myburg joined me and has subsequently taken over as secretary.



Picture of Vivienne at the onset of MND

Gently does it.....

A word of advice for all well meaning volunteers and carers.

I was walking in Sea Point from the bank to the car when I was suddenly on the pavement. Various people ran to my assistance to pull me up. A gentleman jumped out of an armed response car and said “don’t touch her, I will get her up”. He then made sure I was not injured then from behind he gently but firmly he put his hands under my shoulders and put me on my feet. He then made sure that I was stable on my feet. It turned out that he was a trained fireman. Subsequently I have been handled by many carers and I have had bruises and scratches from mishandling. Do not ever allow anyone to pull you up by your arms even if it is somebody strong. You must be handled firmly but gently as you bruise easily. The carer must pay attention to the position of your arms and legs and possibly use pillows to cushion your joints.

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.*

Condolences to the Family and Friends of:

Dr G Mosam, Mary Carstens, Pieter Langerman, Paul Badenhorst, Philip le Roux, Louise White, Sheila Smith, Ulla-Margaretha Tommasi, Rudolf Labuschagne, Abdullah Hendricks, Vivienne Zilberg, Leon du Plessis, Bert Moller, Rosemary Dickinson, Stuart MacFarlane

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

MOTOR NEURONE DISEASE ASSOCIATION of South Africa

P.O.Box 789, HOWARD PLACE, 7450,

TEL: (021) 531-6130

FAX: (021) 531-6131

E-mail: mndaofsa@global.co.za

JOHANNESBURG

TEL: (011) 791-4739

CELL: 082-878-3716

E-mail: keth@futurejhb.co.za