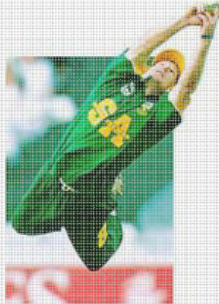


EPILENES

“Epilepsy is not disabling”, says Jonty



He was a South African cricketer, who was especially noted for his feats whilst fielding. Jonathan Neil (Jonty) Rhodes was born on 27 July 1969 in Pietermaritzburg (South Africa). A right handed batsman, he represented the South African national side in both the Test match and one-day international forms of the game. During his career he also played first-class cricket for Gloucestershire County Cricket Club, KwaZulu-Natal and Natal. He is not only noted as a fantastic fielder, one of the best fielders in cricketing history, but also as a quick runner between the wickets and a batsman who likes to keep the scoreboard ticking over. In 1999 Jonty was voted as one of the Wisden Cricketers of the Year and in 2004 he was voted 29th in the Top 100 Great South Africans in SABC3's Great South Africans television series.

A Jonty Rhodes 50 cent coin was made to commemorate the 2003 Cricket World Cup in South Africa. Currently, he tours extensively with the Proteas as the team's fielding coach.

After Rhodes's famous run out of Inzamam-Ul-Haq, he revealed in an interview that he had epilepsy. On hearing this, Epilepsy South Africa approached Jonty to ask him if he would be interested in working with the organisation. He has become a role model to children and youth with epilepsy and has proved that the condition need not be a disabling one.

This is an extract from EPILEPSY SOUTH AFRICA's website and www.wikipedia.org/wiki/Jonty_Rhodes.

*As a role model for children and youth, Jonty responds to numerous emails from this age group. Read more on **page***

THE BIGGEST EVER NATIONAL CHARITY WINE AUCTION!

Raising funds and awareness about epilepsy!

Ticket: R500 per person / R5000 per table of 10 (Includes a five-course meal, plus entertainment, lucky draws and lots of prizes to be won, plus the opportunity to bid on South Africa's top wines.)

For your tickets contact: Noëline de Goede, 021 447 3014/ 084 500 6986 or Neels Troskie, 021 447 3014/ 082 679 9205



EPILEPSY SOUTH AFRICA
National Wine Auction

15 March 2007
Arabella Sheraton Grand Hotel



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Wow! We are proud to present to you our 'transformed newsletter' and to wish our readers everything of the very best for 2007! We wanted to create the 'Wow Factor' to encourage more people affected by epilepsy to get involved in Epinews and to, hopefully, use it as a mouthpiece to voice and discuss epilepsy related issues. Our sincere thanks to our readers for the present contributions.

This edition is jam-packed with interesting articles with a focus on the people behind the scenes, the Epinews Editorial Board and branch Directors of Epilepsy South Africa.

A sincere word of thanks to sponsors Sanofi Aventis for making it all possible.

 **MEET THE EPINEWS EDITORIAL BOARD**

The Board consists of people with epilepsy and can be contacted on: 

René Jarman	011 816 2040	Tim de Villiers	082 925 0404
Nazli Petersen	082 447 9513	Filicity September	021 447 3014

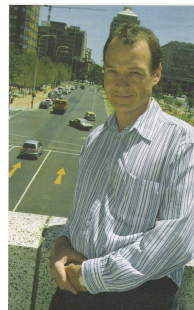


René Jarman works in Fundraising/Awareness creation at the Gauteng branch of Epilepsy SA and has partially controlled seizures. René has been involved with the West Rand support group for people affected by epilepsy

since its launch in August 2001 and compiles the monthly support group newsletter for all Gauteng support groups. She is a keen gardener and has a passion for the written word that includes reading, writing, translating and editing. René is married and has three children and six grandchildren.

* * *

Tim de Villiers has very well controlled epilepsy, is a Civil Engineer specialised in traffic engineering, a keen cyclist, mountain biker, hiker and swimmer. He co-founded Epicare Cape Town, a social support group for people with epilepsy on 6 October 1986 and has Chaired Epicare since. In addition he serves on the National Steering Committee, the Western Cape Board and the Editorial Board of EPILEPSY SOUTH AFRICA and produces Epicare's monthly Brainstorm newsletter.



The Editorial Board invites you to comment on the changes made and to offer suggestions as to how we can improve the newsletter even more.

Nazli Petersen is a single mom, diagnosed with epilepsy since birth, but has been seizure-free for the past 16years. Nazli is very passionate about disability issues and has been working in the disability sector since she started working for the first time. Currently, Nazli is the Secretary to a blind MP.



* * *



Filicity September is the National Director PA of EPILEPSY SOUTH AFRICA. Filicity started working at EPILEPSY SOUTH AFRICA on 1

November 2000 and has been running the Mitchells Plain support group for people affected by Epilepsy ever since. Her involvement with the organisation began soon after she was diagnosed with epilepsy and her main interest is encouraging people with epilepsy and advocating on their behalf for the purpose of uplifting and enriching their lives. Filicity gave a mesmerising talk at the first Epilepsy Conference held in 2000 and has attended and spoken at subsequent conferences both nationally and internationally.

.....
 • The **Penpals' section**
 • has been
 • discontinued due to
 • the lack of
 • responses. The
 • Epinews Editorial
 • Board would like to
 • thank everyone who
 • has submitted their
 • details. We
 • encourage you to
 • contact nearest
 • branch if you need to
 • speak to someone
 • about epilepsy. See
 • the page 8 for the
 • contact details.
 •

ACHIEVERS WITH EPILEPSY

From page 1 ... Jonty Rhodes' response to Michael Treu, one of many fans

Hi Michael

Glad to hear that you love your sport - it is a great way to meet interesting people and see interesting parts of the world! When I went to that first World Cup and crashed into the stumps, I had a few interviews over the next couple of weeks, as you can imagine! Most of the Aussie journo's wanted to know what position I played on the rugby field, as they all presumed that because I was a whitey, I must play rugby in the winter.

Up until then, nobody knew that I had epilepsy - not because I was trying to hide the fact, but just because my parents wanted me to experience a pretty normal existence I had to be careful where I put my head, so never got the chance to play rugby, and even had to give up soccer for 1/2 a season, as I kept getting knocked out. I eventually persuaded my mum to let me play the last 1/2 of the season, by promising not to header the ball - if possible. I played centre-forward, so not much chance of me NOT putting head to ball, especially when goals were on offer!

I had a very mild form of epilepsy, so never had to go on any medication, and the doc's said that I would probably grow out of it by the time I get into my early 20's. The last 2 occasions that I got

knocked out was when I got hit on the head by Alan Donald, and the England bowler, Devon Malcolm!

Both those guys would probably have knocked most people out epilepsy or no epilepsy!

Dealing with young kids and parents over the years, I have come to realize that as with most things, it is the fear of the 'unknown' that most gets to us. I was first diagnosed with my condition in 1975, and hardly anything was known about it then.

Nowadays, with the medication available, you can continue with your life, and never have to feel that you "SUFFER" from epilepsy. Being a successful sportsman already, you will know that you can't always determine the result, but you can decide how you are going to react to the circumstances that you are faced with. You obviously have a good work ethic on the field, and knowing your limitations enables you to overcome them. So never see this condition as something that keeps you from doing things, but rather, as something that helps you grow every day.

Just think, being mentally tougher, thanks to the extra effort or sacrifices you might have to make in certain areas, will ensure that you remain at the top of the selector's list when they start picking their team! Have a wonderful 2005

Cheers

Jonty



David, a symbol of inspiration

Prepared by Kandas Kandawire, Assistant Director, Gauteng Branch

David Matlakala is a person with epilepsy who successfully obtained his National Certificate in Information Technology: Technical Support, NQF Level 4, SAQA ID 24293 (ICDL, A+, N+) from June 2004 to June 2005 at the Bytes Technology Group (Midrand) through the help of EPILEPSY SOUTH AFRICA.

David came to know about EPILEPSY SOUTH AFRICA through a Youth Guide Information Bulletin which he found in Diepkloof in June 2004. This new treasure gave him a feeling of having "the world in his pocket" due to the valuable and insightful information it contained.

His curiosity and need to find out more prompted him to contact the Social Worker at the Gauteng Branch EPILEPSY SOUTH AFRICA and an interview was arranged.



David's life changed dramatically after that. His passion for information technology was mentioned during the interview and the Social Worker assisted David in being placed at the Bytes Technology Group (Midrand).

This achievement has brought David hope and has strengthened his purpose for living. It boosted his self-esteem and self-worth to such an extent that life had new meaning. David now believes in living life to its full, with great vision and a finer spirit of hope and success. Currently, David is studying for his NQF Level 5 in Information Technology. He serves as a symbol of inspiration and hope for people with epilepsy in their quest for a fully balanced life style.

EPILEPSY SOUTH AFRICA, Gauteng Branch is proud of you, David.

The Epinews Editorial Board draws your attention to the achievement of the persons above. We realise that not all stories have happy endings. Share your story with us as it is learning curve for the next person.

"LET'S TALK ABOUT EPILEPSY"

The Epinews Editorial Board dedicates this Page to all people with epilepsy, the young and the not so young, their families and all interested parties. Your jokes, suggestions, messages, etc. on epilepsy and other disability related issues. Raise your burning issues and invite comment from people affected by epilepsy.



The Epicare National Network is an independent non-profit social support network, voluntarily run by people with epilepsy, for all people affected by epilepsy, in association with EPILEPSY SOUTH AFRICA. The aim of Epicare National Network is to link all epilepsy support groups around the country. Please contact Tim de Villiers on 082 925 0404 and Filicity September on 082 368 4189 for more information.

h.nouveau... New Beginning in the Free State & North West Branch!!

Monique Strydom was invited as guest speaker at the Annual General Meeting of the Branch in 2005. She was so inspired by what she saw that she and her husband, Callie, Alice Art and TUKS Rag (University of Pretoria) "adopted" our Residential Care Facility and, Oh! What a difference they have made. The project is called 'h.nouveau' which means 'new beginning'.



This new beginning gives residents an improved home, that started off with artists Cornelius Bosch and Glendine and Harry Erasmus helping the residents paint their own paintings for their flats. We saw new talent born within our residents, which has seen their self-esteem grow.

Our thanks go to Callie and Monique Strydom and to their Charity Trust, to Alice Pitzer of Alice Art, the staff of InPas and Finesse, Hybrid Electrical and the artists for making the lives of our residents 'brighter by the day'.



The artists : Cornelius Bosch and Glendine and Harry Erasmus

The Bill of Rights for People with Epilepsy

The EPINEWS EDITORIAL BOARD would like to challenge all people with epilepsy to indicate what they would like to see in the Bill of Rights for People with Epilepsy in South Africa. People with epilepsy have specific needs which must be stipulated by us and demanded to be met by society at large. The Bill will set a stepping stone in ensuring that we are treated fairly and without discrimination. The input will be submitted to EPILEPSY SOUTH AFRICA for assistance in formulating it into a Bill of Rights. Please submit your input to: Epinews Editorial Board, PO Box 73, Observatory, 7935.

CONGRATULATIONS!

Bridgette Madden from Parow West, Cape Town, for successfully completing the Soduka puzzle which appeared in Epinews Winter 2006, Volume 27 No. 2.

www.epilepsy.org.za

EPILEPSY SOUTH AFRICA launched its new upgraded website on September 2006. Please check all the changes that have been made and post your questions/ comments to info@epilepsy.org.za.

www.FreedomInMind.com

The International Bureau for Epilepsy (IBE) launched a new Freedom in Mind website in 2006 as a joint initiative of the IBE and the biopharmaceutical company UCB. People with epilepsy are invited to express, through art, what freedom from seizures means to them. A major exhibition will be presented during the 27th International Epilepsy Congress in Singapore in July 2007. Check out the website for more information.

Who am I?

I am a life,

A breathing soul,

Insulted by ignorance.

I move amongst the creatures of the earth,

Dance to the rhythms of the beating drum,

Echoing the pain of the unknown suffering

I am a life,

Who are you?

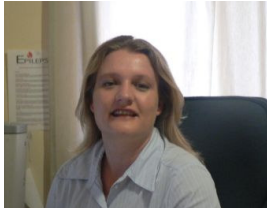
Sent by 'Anonymous'

OBITUARY

EPILEPSY SOUTH AFRICA and the Trustees of the Mick Leary Educational Trust send condolences to Prof. Mick Leary for the passing of his wife, Mrs. Leary on 23 December 2006. Our thoughts are with Prof. Leary at this time.



Well wishes for 2007 from the National Director and some of our Branch Directors at EPILEPSY SOUTH AFRICA



EPILEPSY SOUTH AFRICA National Office would like to wish all our colleagues, partners, clients and friends well for 2007! We hope that 2007 will be filled with joy and prosperity for

each of you and that together we will be able to achieve all our goals for the year!

Kindest regards
Noëline de Goede
National Director

* * *

"You cannot change the direction of the wind but you can adjust your sails." In the same way you cannot move away from the reality of living with epilepsy, but you can chose to live positively with epilepsy and move forward.

Wishing you a successful and happy 2007!

Sujata Pillay, **Branch Director, KZN/ Midlands Branch**



* * *



Happy New Year! Please accept my best wishes for the New Year.

This is a season when many of us take stock of our past, while we also plan for the future. At Epilepsy South Africa – **Free State & North West Branch** we have had a most exciting past year with many changes. I thank all the staff, volunteers, clients and donors for their support and accepting the changes with enthusiasm.

The foundation for a wonderful 2007 has been laid and we look forward to the New Year. We know that our branch will go from strength to strength and we wish the same for all branches of Epilepsy South Africa. For all the beneficiaries of our services... may 2007 bring you much joy and happiness despite the struggles that you are faced with!!

Kindes regards, Gary Westwood, Branch Director

* * *

EPILEPSY SOUTH AFRICA also welcomes the newly appointed Branch Director of the **South Cape Karoo Branch**, Vivian Paremoer and extends our well wishes for 2007.



Season's Greetings

To all our members, colleagues, and friends From Epilepsy South Africa, Western Cape Branch, we wish you joy, peace, hope and



prosperity in the New Year. Let's remain committed to our vision in the provision of equal opportunities for people with epilepsy and other disabilities.

Wendy Nefdt
Regional Director
Western Cape Branch

* * *



One of the nicest things about this time of the year is sending good wishes and remembering good times. So, with special appreciation I thank my colleagues, both at branch and national level, for another wonderful year. It was a pleasure working with each and every one of you!

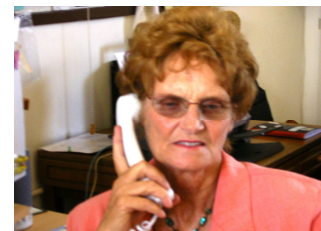
To all members, consumers and volunteers, thank you for your support throughout the past year. Your commitment does not go unrecognized and is highly appreciated.

I also thank you funders (government and others) for enabling us to provide a vital service to and with people with epilepsy.

To all readers of Epinews, I trust that you had a merry festive season and wish you all a wonderful 2007! Magdaleen Badenhorst – Branch Director **Gauteng Branch**

* * *

Make an effort to try to learn from everyone you meet during 2007 and make a habit of taking time to listen carefully to what is being said to you before you formulate your response. You will be amazed at the results each and every time. Every day of our lives brings the opportunity for a new beginning. And there is never a better time than now



Mariana Holtzhausen, Branch Director, **Mpumalanga/ Limpopo Branch**

CANADIAN TRANSROCKIES CYCLE RACE 2006

By Gavin Mackintosh, member of National Office



This story is to try and show fellow people with epilepsy that life need not end with a diagnosis of epilepsy. I am 47years old and have been living with epilepsy for the past 30 years.

One year ago my wife and I decided to visit her sister and her brother-in-law in Canmore, Canada. While in Canada by way of an “excuse”, we would take part in the TransRockies mountain bike race. This is a seven day off road mountain bike (MTB) event for teams of two in various categories. The category we entered was the Mixed 80+ (combined ages over 80). Our training started in August 2005, approximately a year before the event. As we had done a similar multi-day off road event in South Africa called the Cape Epic a few years previously, we thought we knew what type of training we needed to complete the event without excessive strain and enjoy scenery and areas that would otherwise be inaccessible. Little did we know!

As the event took place from the 6th to the 12th of August 2006, the greatest part of our training was done during the winter months of 2005, We were expecting temperatures of between -5 and +30 degrees during the race, but were not too concerned, as I do not take too well to excessive heat. During this time, some of our MTB friends also decided to enter, so this made training easier with a common goal. In addition, my In-laws decided that they would “second” us (I think it was more a case of come and see us suffer!). The training went fairly well and soon we were prepared to head off to Calgary, Canada.

The flight to Calgary is long and entails a 10,5 hour leg to London with a 6 hour wait, followed by another 8,5 hour flight to Calgary, “losing” a total of 8 hours along the way due to time zones. My epilepsy is generally well controlled and I intended taking my medication at the normal time in the appropriate time zone.

During the race I aimed to increase my dosage to compensate for the additional stress. In retrospect the delay in taking my medication due

to time zones was an error. We arrived in Calgary on Thursday afternoon and the following day collected our camper (called an RV or Recreational Vehicle) and headed off to the start of the race in Fernie, a few hundred kilometres to the South. We arrived in Fernie on Saturday to register and complete final arrangements before the start the following day.

The morning of the race was clear and sunny. My wife went off to the ablutions and on her return I recall looking at her rather concerned face as she told me that I had just had a tonic clonic seizure. I asked where I was and she told me I was in Canada to do the Transrockies and asked if I was up to it as the start was within 3 hours. Although my right shoulder was sore, my tongue slightly bitten and I had a headache, the seizure had not been too severe. We had done the training, had spent a lot of money to participate in the event, and I was determined to give it a try. The seizure had probably been brought on by the stress of travel, the heat and the knowledge that, although I had successfully completed many other cycling events, this was probably going to be the most testing.

The following 7 days we cycled a total of 556 km in 50 hours and 19 minutes, climbing 13 020 metres with temperatures of 41 degrees C on some of the stages and snow and rain on others. It was mostly technical, slow riding with some severe portage (“hike-a-bike” in Canadian) sections. Fortunately on the last day we got our “act together” to finish the day’s stage in 3rd place in our 80+ category. This really ended the event on a good note.

Having lined up on the starting line feeling very “second hand” with serious doubts of completing one stage, never mind the entire event, I am very proud to say that I did not give up even when times were tough.



National office makes EPILEPSY SOUTH AFRICA services visible in the Eastern Cape



The National Social Development Manager, Tshidi Mohapeloa, visited the Eastern Cape to strengthen the working relationships with organizations rendering services to people with disabilities in the province.



🕒 EVENTS CALENDER: JANUARY – JUNE 2007 🕒

Please contact your branch to find out more about these events on 0860 374 537.

DATE	EVENT	CONTACT PERSON
15 March 2007	National Wine Auction	Noëline de Goede 021 – 447 3014
17 April 2007	National Skills Development meeting Khulani Committee	Marina Clarke 021 – 447 3014
18 – 20 April 2007	National Directors' meeting	Noëline de Goede 021 – 447 3014
21 April 2007	National Board meeting	Noëline de Goede 021 – 447 3014
18 – 24 June 2007	National Epilepsy Week	Noëline de Goede 021 – 447 3014
21 June 2007	National Epilepsy Day	Noëline de Goede 021 – 447 3014
8 – 12 July 2007 15 January 2007 16 March 2007	27 th International Epilepsy Congress Abstract submission deadline Early registration deadline	www.epilepsysingapore2007.org



SKILLS DEVELOPMENT UPDATE

Prepared by Marina Clarke, National Economic Development Manager, who can be contacted at EPILEPSY SOUTH AFRICA National Office for more information on the various interventions.

Bursaries The Services SETA approved 200 bursaries in a joint project between Epilepsy SA and the SA National Council for the Blind for full qualifications and accredited skills programmes. The value of these bursaries vary between R6,000 for non-Services SETA qualifications to R12,000 for Services SETA qualifications. Should you require any information in this regard, please contact Marina Clarke at the National Office of Epilepsy SA.

Epilepsy EAP One of the most exciting new ventures is the development of a new Employee Assistance Programme (EAP) focusing on epilepsy in partnership with the Services SETA. This Programme will provide insight and information on employees with epilepsy to employers and form part of the Services SETA's EAPs. We are hoping to have this EAP ready to be launched at the Directors/Board meetings to be held in **Cape Town in April 2007**.

Instrumental Enrichment Programme The International Center for the Enhancement of Learning Potential (ICELP) was established with the goal of continuing and expanding the educational and psychological work initiated by Prof. Feuerstein. The work of the ICELP is based on the theories of Structural Cognitive Modifiability and Mediated Learning Experience, which serve as a basis for three applied systems: the Learning Potential Assessment Device (LPAD), Instrumental Enrichment (IE) cognitive intervention program, and Shaping Modifying Environment.

This is a new developmental programme on the African continent with its origin in Israel. The Services SETA anticipates establishing the Programme in South Africa during 2007.

The Programme requires participants to attend a series of training modules in order to become a mediator (the term used in the Programme for a facilitator/trainer). This will be followed by a training of trainers programme. The Services SETA plans to establish a core group to continue with training prior to entering the training of trainers programme.

It is anticipated that between 100 and 150 mediators will be trained by an Israeli company in January/February 2007 in South Africa. Following discussions between Epilepsy SA and the Services SETA a pilot project was identified for people with epilepsy, as well as blind and partially sighted people.



Singapore 2007

27th INTERNATIONAL EPILEPSY CONGRESS 8th - 12th July

EPILEPSY SOUTH AFRICA

Please contact any of our branches on **0860 EPILEPSY** or groups for advice or information or visit our website at

www.epilepsy.org.za or email info@epilepsy.org.za

OFFICE	ADDRESS	PHONE/ FAX
NATIONAL OFFICE	PO Box 73, Observatory, 7935	021 447 3014/ 021 448 5053
BRANCHES		
KZN DURBAN & COASTAL	PO Box 47799, Greyville, 4023	031 309 1370/ 031 309 1651
WESTERN CAPE	PO Box 24573, Lansdowne, 7779	021 703 9420/ 021 703 2529
SOUTH CAPE KAROO	PO Box 107, Knysna, 6570	044 382 2155/ 044 382 3545
KZN MIDLANDS	PO Box 2165, Pietermaritzburg, 3200	033 394 1041/ 033 394 1032
FREE STATE & NORTH WEST	PO Box 167, Parys, 9585	056 811 5959/ 056 811 5786
GAUTENG	PO Box 1070, Springs, 1560	011 816 2040/ 011 816 1501
MPUMALANGA	PO Box 55, Dullstroom, 1110	013 254 0161/ 013 254 0290
SUPPORT GROUPS		
Epicare Cape Town	Tim De Villiers	082 925 0404
Epicare Mitchell's Plain	Filicity September	082 368 4189
Epicare Durban	Vinoo Singh	031 309 1370
VNS Support Group	Roweena Stewart	082 822 3602
Keto Club – Gauteng	Lynn-Anne Hooper	072 477 0258
Support Group – West Rand	Roweena Stewart	082 822 3602
Support Group – East Rand	Leilane Maré	011 811 1590
Support Group – Daveyton	Thandekile Shabalala	011 816 2040
Support Group – Pretoria	Leilani Maré	011 811 1590
Support Group – Soweto	Thokozile Mtshali	011 816 2040
Support Group – Knysna	Mina Stuurman	084 665 5746
Support Group – Kranshoek	Julie Andrews	044 533 9245
Integrated Group – Mossel Bay	Bets Potgieter	082 851 0748
Support Group – Touwsrante	Christine Ruiters	073 182 5835
Support Group – Crags	Bernie Plaatjies	073 229 4962
Support Group – Siyabuswa	Maria Motau	013 973 1836
Support Group – Delmas	Sarah Zwane	013 665 2619
Support Group – Dullstroom	Judith Maseko	013 254 2619
Support Group – Elukwathini	Thoko Nhlapo	082 939 1672
OTHER		
Childline South Africa	32 Chicks Drive, Durban North, 4051	08000 55 555
Lifeline Southern Africa	PO Box 32201, Braamfontein, 2017	0861 322 322
National AIDS Helpline		08000 12 322
National Women's Helpline		0800 150 150
South African Human Rights Commission	Private Bag 2700, Houghton, Johannesburg, 2041	011 484 8300



