Mick Leary Educational Trust bursary helped Dr. Toussaint

Dr. Tanya Toussaint, graduated with MBChB on the 11th December 2006 and have started my internship at the Free State Academic Complex where I will be for the next two years. My journey with epilepsy started just after I had an operation to remove my appendix in 1997. I woke up three days after the operation, having had two tonic clonic seizures and what felt like a truckload of medicine to keep me sedated.

Following that, I had a normal CT brain scan and a period of two years without seizures. Then began a game of hopscotch between myself, epilepsy and medicine. In this time I matriculated and, with the help of the Mick Leary Educational Trust and EPILEPSY SOUTH AFRICA, began my medical studies. My years became littered with heavy textbooks, a white coat and a trusty stethoscope. And always there was epilepsy, reminding me he was still there.

At the end of last year I donned my gown and joined my class in receiving my MBChB degree. And still there was epilepsy, haunting my steps.

I’m now in my fifth month of internship at the Free State Academic Complex of Hospitals and, God be glorified, I have not had a single seizure.

“**To all those suffering from epilepsy: Be strong and be encouraged.**

**To those supporting those with epilepsy: My heart is with you. I believe your’s is sometimes the harder job.**

**To epilepsy: You have taken enough. No more.**

Dr. Toussaint is one of the 24 students who has received bursaries from the Mick Leary Educational Trust since it’s inception in 1998. Read more on page three.

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**Wine Auction creates new opportunities for people with epilepsy**

EPILEPSY SOUTH AFRICA hosted their first National Charity Wine Auction on 15 March 2007 at the ArabellaSheraton Grand Hotel, Cape Town to generate awareness and raise funds.

Combining excellent venue, food and wines, entertainment by MC Soli Philander and Viva Vocé, and first class auctioneer, Joey Burke of Auction Alliance, raised an impressive R191,785. The highest bid was R20 000 for a Pearl’s Gate 225 litre barrel of Cabernet Sauvignon/ Shiraz blended by master wine maker Altus Le Roux.

Well-known personalities with epilepsy, Jonty Rhodes, Pat Pillai and Gerri Rantseli, attached their names to the awareness campaign.

National Director, Noëline de Goede expressed thanks to “everybody involved in our National Charity Wine Auction who assisted us to turn obstacles into true potential!”
Welcome to the next edition of our energised newsletter. This edition shows you how you can participate to make the newsletter yours. It is filled with stories of people with epilepsy, their achievements and an introduction to the people who govern the organisation. Give us more of your stories and views on life in general.

National Epilepsy Week gives you the opportunity to become involved in the organisation’s activities. Contact the Branch nearest you on 0860 EPILEPSY for more information.

The Editorial Board invites you to contact us should you have any news or ideas for the newsletter on the contacts provided on this page.

The Epinews Editorial Board thanks our sponsors Sanofi Aventis for their continuous support.

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**MEET A FEW OF OUR NATIONAL STEERING COMMITTEE**

I met a young man in a pharmacy. He complained that he had bitten his mouth whilst having a seizure. It was all new to him. He had not heard of Epilepsy South Africa so I gave him their details. He left, pleased that there was somewhere to turn to, and I was happy to have helped in a small way.

I am a Board member of the Gauteng branch and the National Chairperson of the National Board of Epilepsy South Africa, but firstly I am the mother of a daughter with epilepsy and this young man could have been my son.

I have learnt a great deal and gained insight into my daughter’s condition by being involved in an epilepsy support group and the Management Boards of the organisation. I strongly believe that we all have a social responsibility to assist our fellow man in any way we can. This is my small contribution.

**Rowena Stewart, National Chairperson**

I was born in Soweto, studied Social Work at the University of Zululand near Empangeni and was introduced to Epilepsy South Africa (then SANEL) in 1990 as a Social Worker. This was the beginning of a long relationship with the organisation and with people with epilepsy.

I achieved a lot in my nine years at the Gauteng Branch especially the opportunity to provide strategic input into the process that led to the establishment of the new, fresh and vibrant Epilepsy South Africa in 2002. The experience that I acquired prepared me well for my present position as National Executive Director of S A Federation for Mental Health.

It is a great privilege for me to serve now on the National Board of Epilepsy South Africa as Vice-chairperson, a great organisation that is transforming the lives of people and making society ever more conscious of vulnerable communities and holding society accountable. I am proud to be part of a movement for and by people with disabilities and pledge to stay committed to upholding the rights of persons with disabilities.

**Solly Mokgata, National Vice-chairperson**

My involvement with Epilepsy South Africa has been very fulfilling and spiritually enhancing. It has given me a sense of responsibility. It is a good feeling to be associated with the organisation.

My nephew had epilepsy from the age of two, lived a normal life, but sadly passed away at the age of sixteen. I have therefore, indirectly, been affected by epilepsy for many years and jumped at the opportunity to join the National Steering Committee to support the work of Epilepsy South Africa. Since joining the team, many more people have been informed of epilepsy and now understand it a lot better because I invite them to give talks on epilepsy.

**Georgina Mbambo, NSC member**
Sue Viljoen lived in Gauteng before she moved to Knysna in 1985. She was employed as a Human Resources Executive in a major corporate company and later entered into a labour relations and training consultancy. She was very involved with the Easter Stamps drive for Cripple Care and raised large amounts of money for this cause. When she moved to Knysna she once again became involved with the sale and distribution of Easter Stamps and was instrumental in facilitating the setting up of the APD Protective Workshop in Hornlee.

Looking for another challenge Sue offered to assist our organisation and was elected to the Management Committee. Her loyal help, assistance, wisdom and life-experience assisted the Branch in making many, often difficult and challenging paradigm shifts in order to remain focused and dynamic.

When the organisation was renamed Sue was voted Chairperson in recognition of her wisdom and guidance that would be heavily taxed in order to ensure that the organisation would be able to deliver on their mandate.

Sue has an amazing knack of noticing the names of people – even those serving tea and biscuits and thanking them in a manner that honours their service. This is carried through in all her dealings with all the people we meet. Her innate respect for everyone and their contribution to society is something we could all aspire to and thereby make the world a much better place. Sue Viljoen, Chairperson of the Branch Committee of the South Cape/ Karoo Branch

Mr Modise is presently the Chairman of a company called Rofara Investment Holdings. “For the next six months of 2007 I challenge the Management Boards, Directors, staff, members and clients of Epilepsy South Africa to expect more from themselves and to set all their goals higher. Don’t be afraid to challenge yourself or to choose the most difficult path. The journey may appear to be more difficult, but it can never beat the view from the top! All my best wishes to you all for the rest of 2007! Kgomotso Modise, Chairperson of the Board of the Gauteng branch of Epilepsy South Africa

I was born in Limpopo Province and matriculated in 1997 with an exemption. I completed a Computer Clerk Certificate with distinction in 2000. I enrolled for a Diploma in Information Technology at UNISA with the aid of the Mick Leary Trust. I partially completed the course, with three distinctions. In 2002 I was employment at TSA as a Student Facilitator and as a lecturer in Secretarial Studies and Computer Programming for four years. I am presently employed as a Legal Secretary for a firm of attorneys. Ms Rhoda Mutaung

The Mick Leary Trust granted me a Bursary to obtain my National Diploma in Accountancy. I will be completing my studies at UNISA in 2008. This encouraged and inspired me to focus on people with epilepsy in the Open Labour Market. I studied, developed my entrepreneurship and can now establish my own enterprise.

Learning that perseverance is the mother of success, I now act as a mentor for the youth and people with epilepsy. I dedicate my success to people with epilepsy and to the Mick Leary Trust. Lebogang Maruloloa

I am in my final year in Pharmacy at the University of Kwazulu Natal-Westville. I’ve had epilepsy for 20 years and with the help of many people, including Epilepsy South Africa, have made it to where I am. My youth was extremely stressful due to financial and family difficulties. Fortunately the Mick Leary Trust paid my tuition fees in 2002 and 2004. I was also awarded the Department of Labour Bursary for persons with disabilities for the past three years.

I will be serving my internship in 2008 and doing community service in 2009. After that I will be a qualified pharmacist! My advice is; believe in yourself, anything is possible. Don’t let epilepsy stop you from achieving. Mbalenhle Funeka Mkhize
**EPILEPSY SOUTH AFRICA CHARTER**

The Epinews Editorial Board has included an insert containing the Epilepsy Charter of EPILEPSY SOUTH AFRICA. This Charter is synonymous with the Disability Rights Charter of South Africa that “reflects demands from disabled people.

The aim is to promote equal opportunities for all disabled people. It is a document which asserts the right of all disabled people to live independently in a safe environment and in a society free from all forms of discrimination, exploitation and abuse” (White Paper on the Integrated National Disability Strategy, 1997:17).

Is the Epilepsy Charter representative of the needs and rights of people with epilepsy? What would you like to see in the Charter? Please send your comments to Epinews Editorial Board, EPILEPSY SOUTH AFRICA, PO Box 73, Observatory, 7935 and it will be printed in the next edition of Epinews.

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**A story of hope and perseverance**

Nombulelo Fanti is 34 years old and lives in Robolo, Knysna. When she married in 1992, her husband did not inform her that he was HIV positive and sadly Nombulelo tested positive the following year, but she had the strength to disclose her HIV status.

She has two children, a thirteen year old daughter and an eight year old son. Both children are HIV negative, although her son did develop epilepsy at the age of two. She and her children were abused by her husband and she was forced to get an interdict against him.

Nombulelo approached the South Cape/Karoo Branch of Epilepsy South Africa for assistance. A sewing machine was donated and together with government grants and the income from sewing, a determined Nombulelo managed to buy school uniforms, pay school fees and to survive.

Nombulelo started a soup kitchen with the help of the Knysna AIDS Council and presently feeds 35 children who are HIV positive or whose parents are infected.

She is involved with the Knysna epilepsy support group, the annual National Epilepsy Week celebrations and is an honoured volunteer of Epilepsy South Africa, Hospice, FAMSA and the AIDS Council. Her son, as bright as a penny, is in Grade 3 and is being treated for his seizures by Dr. Potgieter of Tygerberg Hospital. Her daughter attends a local Private School sponsored by a friend.

**Nombulelo is an inspiration to all of us and we trust that her story will inspire you!**

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**Masters in Philosophy in Disability Studies, by Filicity September**

According to the Social Model of Disability in the White Paper on Integrated National Disability Strategy (1997) disabled people are regarded as equal citizens and have the same responsibility, opportunity and rights as able-bodied citizens. I decided to further my own education on the basis of this statement and prove that a disability does not make one less equal in spite of having epilepsy.

UCT offers a Masters in Philosophy in Disability Studies course to disabled people in national and provincial governance structures; staff of provincial offices on the status of disabled people; disability activists; health professionals; social workers; teachers; service providers in public and private sectors; human resource managers; policymakers; lecturers and students in different faculties.

I applied and was accepted and started the two year course in February 2007. The course comprises “seven taught modules, a research protocol and a minor dissertation”. As a MPhil student, I and my two fellow pupils have been commissioned to promote the course among the disability sector this year on the request from the course convenor, Prof. Theresa Lorenzo.

The course outline can be viewed on Page 143 to 144 of UCT Faculty of Health Sciences Student Handbook 2007 or www.uct.ac.za. Closing date for application is 31 October.

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**The parable occurrence**

Being lost in a sea of pain,
Refusing to be saved,
A man of lesser means came by
Insisting to give aid.

I was dumb-struck, could not speak
The words of gratitude,
But thankful none the less
For having been rescued.

Another man with babe in cart
Abhorred the sight of blood;
He said he could not help a man
Who had no wealth to flood.

The commoner bid the law to halt,
(they paused to answer duty)
Yet failed to see the dire need
To carry one deprived of beauty.

Jesus told a tale akin
To this event which proved be true –
He said of neighbours: they be men
Who show compassion, mercy too.

By Alister Arendse, August 1993
**Dr Jocelyne Kane-Berman** was the medical superintendent of Groote Schuur Hospital for 25 years and was also the first woman to hold the position of Deputy Director General and Head of the Department of Environmental and Cultural Affairs and Sport in the Western Cape. Since retiring in 2000, Dr Kane-Berman has worked as a consultant for both the Eastern and Western Cape Health Departments. Presently, Dr Kane-Berman is the Chairperson of the Irma Stern Museum Committee as well as a Trustee of the Mick Leary Educational Trust. Dr Kane-Berman is an enthusiastic amateur bird watcher, an environmentalist and a devoted grandmother.

**Ms. Amelia Jones** is the Chief Executive Officer and the first black female Executive Director of the Western Cape Community Chest and heads an organisation of 28 permanent staff and over 9,000 volunteers. Before joining the Community Chest Ms Jones pioneered and implemented a very successful ‘Capacity Building & Training Programme’ that is now in its 14th year. Amelia serves on the board of Epilepsy South Africa and on various Civil, Corporate and Government institutions and is a sought after speaker and trainer both nationally and internationally.

**Mrs. Noëline de Goede** qualified in 1996 as Social Worker at the University of Stellenbosch. She worked at Bouncing Bears and Marie Stopes during 1996 and 1997. Mrs. De Goede moved on to work at Cape Town Child Welfare Society from 1997 to 2001 and since then as Senior Social Worker at Epilepsy South Africa Western Cape Branch till March 2004 and was appointed as National Programmes Manager at National Office till June 2004. She was appointed as Acting National Director since June 2004 and appointed as National Director of Epilepsy SA since February 2005. Mrs. De Goede completed a Management Advancement Programme (MAP) at WITS Business School in 2005. In 2005 Mrs. De Goede was elected as Trustee of the Mick Leary Educational Trust.

Her future plans include making Epilepsy SA a favorite “charity” organisation within South Africa and to ensure that people with epilepsy and people with other disabilities are included in mainstream society.

**Professor Bryan Kies** is a Specialist Neurologist at Groote Schuur Hospital and University of Cape Town. He acquired the following accolades: MBChB (1971); FCP (1976); MRCP (1976); FRCP (2005) and FCNeurol (2005). His special interests include Epilepsy, Parkinson’s Disease, Headache and Medical Education, which is also included in publications.

Prof. Kies practiced Neurology in Cape Town, London and New Zealand. He presented papers at National and International Neurology Conferences in Australia, Peoples Republic of China, India, UK, Ireland, Spain, Portugal, Norway, Chech Republic, Namibia, Zimbabwe and Brazil.

Prof. Kies has been Investigator in international drug trials for Parkinson’s Disease, Epilepsy, Migraine and Stroke. He is the Secretary of the College of Neurologists (CMSA) and past Treasurer of the Neurological Association of South Africa. Prof. Kies’ interests in epilepsy led him to being elected as Trust of the Mick Leary Educational Trust in 2001.

The other Trustees of the Mick Leary Educational Trust include: **Mr. Sitembele Africa Languza**, previous bursary holder of the Mick Leary Educational Trust who became a Trustee of the Mick Leary Educational Trust in 2003. Mr. Languza has developed profoundly over the years and is currently working at the Office on the Status of Disabled People in Mafikeng.

**Mr. Vusi Mahlasela**, an artist, who was elected as Trustee since the inception of the Trust in 1989.
The South Cape/ Karoo Branch is situated in Knysna, off Rio Street. It is in the heart of Garden Route and is surrounded by tourist attractions like, the Elephant Park, Monkey Land, Birds of Eden, Knysna Lagoon, The Heads and the beautiful sea. The Residential facility houses 60 people with epilepsy and or other disabilities and 20 day visitors. Their Outreach programme stretches to The Crags and George also covering deep rural areas and farms.

**Ronald** and **Nicky**, residents of the Residential facility and members of the Knysna Marathon Club, competed and completed the Two Oceans Marathon. This year they will take part in 2007 Comrades Marathon.

Here are some of their Workshop Products:

- Wooden furniture
- Quilts
- Garden Furniture

The person, who is heading the South Cape / Karoo Branch, is the new **Branch Director, Vivienne Paremoer**. The Epinews Editorial Board formally welcomes Vivienne to the organisation and wishes her well for the future.

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<thead>
<tr>
<th>SUPPORT GROUPS</th>
<th>Mina Stuurman</th>
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<tr>
<td>Support Group – Knysna</td>
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<tr>
<td>Support Group – Kranshoek</td>
<td>Julie Andrews</td>
<td>044 533 9245</td>
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<tr>
<td>Support Group – The Crags</td>
<td>Berlie Plaatjes</td>
<td>073 229 4962</td>
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PROUDLY SOUTH AFRICA ANNOUNCEMENT

EPILEPSY SOUTH AFRICA was a finalist in the category Nation Builder of the Year of the Proudly South Africa HomeGrown Awards. The winners announced at the Awards Ceremony in Johannesburg on 24 May 2007 were “The Chaeli Campaign - corporate.

EPILEPSY SOUTH AFRICA TV ADVERT

EPILEPSY SOUTH AFRICA will be launching our brand new TV advert (see below) featuring celebrities with epilepsy: Gerri Rantseli, Pat Pillai and Jonty Rhodes.

EVENTS CALENDER: JUNE – DECEMBER 2007

<table>
<thead>
<tr>
<th>DATE</th>
<th>EVENT</th>
<th>CONTACT PERSON</th>
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<tr>
<td>16 June 2007</td>
<td>Epilepsy Street Parade</td>
<td>Mpumalanga/ Limpopo: 013 254 0161</td>
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<td>18 June 2007</td>
<td>Awareness &amp; Media release</td>
<td>Mpumalanga/ Limpopo: 013 254 0161</td>
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<td>18 – 24 June 2007</td>
<td>National Epilepsy Week</td>
<td>Tshidi Mohapeloa: 021 447 3014</td>
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<td>21 June 2007</td>
<td>National Epilepsy Day</td>
<td>Tshidi Mohapeloa: 021 447 3014</td>
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<td>19 June 2007</td>
<td>VIP Invite guest</td>
<td>Mpumalanga/ Limpopo: 013 254 0161</td>
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<td>20 June 2007</td>
<td>Director’s Challenge</td>
<td>Mpumalanga/ Limpopo: 013 254 0161</td>
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<td>21 June 2007</td>
<td>Director’s Challenge</td>
<td>Western Cape: 021 703 9420</td>
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<td>June – Dec 2007</td>
<td>The Herald Car Raffle</td>
<td>South Cape Karoo: 044 382 2155</td>
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<td>July 2007</td>
<td>Pick ‘n Pay Knysna Oyster Festival</td>
<td>South Cape Karoo: 044 382 2155</td>
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<td>- Pancake Stall</td>
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<td>- Ride4Change Challenge</td>
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<td>28 August 2007</td>
<td>Annual General Meeting</td>
<td>South Cape Karoo: 044 382 2155</td>
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<td>7 September 2007</td>
<td>Casual Day</td>
<td>Neels Troskie: 021 447 3014</td>
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<tr>
<td>October 2007</td>
<td>Dr. Potgieter’s visit to South Cape/Karoo</td>
<td>South Cape Karoo: 044 382 2155</td>
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<td>17 October</td>
<td>International Day for the Eradication of</td>
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<td>Poverty</td>
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<td>5 November</td>
<td>National Children’s Day</td>
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<td>25 November</td>
<td>Activism on No Violence Against Women</td>
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<td>1 December</td>
<td>World Aids Day</td>
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<td>3 December</td>
<td>International Day of Disabled Persons</td>
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<tr>
<td>5 December</td>
<td>International Volunteers Day</td>
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Please contact your branch to find out more about these events on 0860 374 537.
It is a rare breed of person who has the ability to take a devastating ordeal and turn it into the greatest possible blessing for themselves and others.

Lynn Jansen Van Rensburg is such a person. After seeing articles in the press on the tribulations of people having seizures in the streets of King William’s Town, she contacted our office with advice on how the public can best deal with these distressing situations.

Life for Lynn was pretty normal. At the age of 32 she was happily married to Michael and had three lovely daughters, twins Samantha and Nicole and the youngest, Michelle. She loved her job and had been with the same company for 15 years.

Then the nightmare began. Lynn started having Temporal Lobe seizures. She was losing control. She forgot the names of people she knew and could not remember how to change gears.

Lynn was terrified and confused by this monster that seemed to have entered her mind and did all she could to hide the truth from her husband and family.

However, this conspiracy of silence did not last. Lynn experienced a seizure at home and lost consciousness for nearly an hour before her youngest daughter Michelle found her.

A doctor was called and at last a name was put to the face of the monster that was destroying her life and bringing chaos into the peaceful haven of her loving family.

Temporal Lobe Epilepsy was, for Lynn, a frightening condition to live with as she had always prided herself on her ability to function well. Suddenly she was out of control and was informed that she would have to learn to live with the condition for the rest of her life.

Lynn lost her job and the cost of medication was about R1700 per month excluding the medical-aid contribution. The worst was the fear in the eyes of her family who could not comprehend what had happened to mom. The final pain was when her driver’s license was revoked as she could no longer be trusted to function safely behind the wheel.

A miracle finally came in the form of Cape Town neurosurgeon, Dr James Butler who, with Dr. Melvill operated on Lynn. She says that she was reborn on the 1st of March 2005 and given her life back. (She has not had a seizure since the operation and was having 7-10 seizures a day.)

Most people would have left it at that but Lynn had a calling to share experiences, strength and hope with others affected by the brutal and misunderstood condition called epilepsy. From being a victim Lynn now had a dream and a vision. The very thing that nearly destroyed her had become her reason for living.

Lynn now runs one of the largest epilepsy support groups (65 members) in the country and networks with affected people as far as the UK. Her support group meets at a local King Williams Town Wimpy on Wednesdays at 6pm for a “chocolate chat”.

Lynn’s epilepsy newsletter and personal story reaches many people each month and is supported by many leading businesses in the Eastern Cape. Lynn also deals with about 15 calls per week from those seeking information, help and support.

The most precious reward so far was to win back the trust and love of her family and be a normal mum again – even though Lynn admits it is also very special to be independent and be allowed to drive her car again!

Lynn has one last dream and that is to carry her vision into the townships where a great number of people are affected by epilepsy and are often persecuted for their condition due to the incorrect assumption that they are bewitched. (The article was shortened for the newsletter. Full story available on request.)

Source: Steven de Kiewiet (The Mercury)