

## CALENDAR

2009

### OCTOBER

22 SAHA Participation

### NOVEMBER

14 Johannesburg Info/Support Meeting

26 JHB PACE Presentation Prof AO

28 Cape Town Info/Support Meeting

28 Bloemfontein Info/Support Meeting

28 Pretoria Info/Support Meeting

### DECEMBER

4 Durban Info/Support Meeting

2010

### JANUARY

17 PACE Half Ironman Fundraiser

### JUNE

7 World Heart Rhythm Week

11 Start World Soccer Cup

IBANDLA LOKUTHWALISA ABAHLUSHWA NGOKUSHAYA  
KWENHLIZIYO  
[www.paceafrica.org.za](http://www.paceafrica.org.za)

### INHLOSO YETHU

Ngokuthwalisa iziguli nangokukwazisa abantu nangoku cwaninga izindaba ezintsha zokwazi, uPACE uzama ukuvimbisa ukufa oku-bangwa ngokushaya kwenhliziyo ngendlela engafanele.

### IZIMPAWU

- Ukuquleka okungavamile
- Izimbhakubhaku nenzululwane nephika
- Isifuba esingezwakali kahle esibuhlungu noma isicindezelo uma umzimba usetshenziswa
- ukuba nesiwombe sesifo esingachaziswanga

### Uma ubenesihlobo esishone:

- Emva kokujima noma ukwelula umzimba
- Ngokuminza kanti ekwazi ukuhlamba kahle
- Engozini yemoto kanti ekwazi ukushayela kahle
- Uma silele
- Uma kushaye ucingo noma kukhale insimbi yokuvusa
- Ngendaba yephika noma isithuthwane
- Ngendlela engamangalisi noma ngokuphathwa yinhliziyo emva kwezimpawu zokuquleka ezingavamile

PACE aims to Prevent Arrhythmic Cardiac Events which can lead to sudden cardiac arrest by advocating arrhythmia education, awareness, support and prevention

# PACE PRESS

Prevent Arrhythmic Cardiac Events

Volume 2

Newsletter

October 2009

## DISCOVERY OF ROGUE GENE

Hi Everyone,

We are very happy to be distributing PACE newsletter no 2!

We have been expanding at a rapid "PACE" which is sure to continue as a recent PACE and CASSA (Cardiac Arrhythmia Society of SA) meeting highlighted our valuable synergy.

We have also acquired the strategic planning and fundraising services of MSM (Medical Society Management) which ensured funding from MEDTRONIC Foundation International to continue our operations. This was complemented by much appreciated individual and company contributions.

With Arrhythmia Support organizations being established worldwide, even as far as Japan, South Africa proudly was the 1<sup>st</sup> country to create awareness in pharmacies during World Heart Rhythm Week. We distributed checklists and "pulse" cards at 100 pharmacies! We also established 7 support groups in SA. These groups provide great opportunities to gain information, share experiences and contribute ideas.

Prof AO's Marathon des Sables race also raised R20 000 to start a PATIENT SUPPORT FUND! while Juliet Rogan our Durban Representative, hosted the PACE Comrades Marathon refreshment station 38!

PACE enjoyed great media exposure locally and internationally and continues to create awareness at pharmacies and elsewhere.

2010 promises to be an exciting year. We hope to initiate CPR/AED training in schools and create much awareness during the soccer world cup!

Finally, without very dedicated PACE volunteers, nothing would have been possible to date. We are very grateful for their commitment.

Thank you very, very much!  
Lusan Luscombe PACE CEO

Research teams from the faculty of Health Sciences of the University of Stellenbosch, assisted by colleagues from the Universities of Hamburg and Munster have recently identified the rogue or defective gene that causes a type of hereditary heart disease. The disease, known as Progressive Familial Heart Block (PFHB) type 1, affects the heart's electrical system. Heart block causes palpitations, light-headedness and fainting. PFHB can occur at any time in life. As the disease may progress to a complete heart block, the successful management depends on the timeous fitment of a pacemaker. The groundbreaking research, conducted over a period of longer than 30 years, was initiated in the 70's by Prof Andries Brink, a Cardiac Specialist and former Dean of Stellenbosch University's faculty of Health Services. His son, Prof Paul Brink, Internist and Geneticist of the same University and Vice-President of PACE, continued his father's quest for the isolation of the cause of PFHB.

A breakthrough for South African medical science, this discovery gives hope to sufferers, who can now get advance warning of their condition and seek the necessary treatment. It will also assist academic and medical staff to gain a better understanding of other conditions that affect the heart's electrical system. By administering a blood-based test, family members at risk can be identified and treated. In the 1970's, Brink Snr treated an infant born with a slow heart rate in Tygerberg Hospital. This child's only hope of survival was the implantation of an artificial pacemaker. He soon became aware of another young child with a similar condition and when he found out that the two children were closely related, he realised that the condition could be genetic. Dr Marie Torrington, a Genealogy Specialist, uncovered that this hereditary heart disease was brought



Prof Paul Brink, Eric Schulze-Bahr, Valerie Corfield, Olaf Pongs and Andries Brink.

into South Africa by a Portuguese immigrant at the end of the 17<sup>th</sup> century. This man married a woman of Dutch descent and genetics has carried the rogue gene down all the generations since then. Every South African suffering from PFHB today is descended from this couple.

Following in his father's footsteps, Prof Paul Brink, assisted by Molecular Geneticist Prof Valerie Corfield, began a study into the identification and location of the defective gene that caused the condition. They identified 71 carriers of the gene in three families descending from the Portuguese immigrant and his Dutch wife of whom 48 had pacemakers implanted. Professors Brink (jnr) and Corfield's extensive research narrowed down the probable locus of the gene to an area encompassing about 80 genes on chromosome 19.

At approximately the same time, Prof Olaf Pongs of the Centre for Molecular Neurology of the University of Hamburg researched a link between gene TRPM4 on the 19<sup>th</sup> chromosome and PFHB type 1. The subjects of his study were all Afrikaans South Africans. He contacted the South African research team, stating his interest in a particular gene in their search area and requested them to examine the specific gene. *The two research groups decided to join hands, which ultimately confirmed that the gene Pongs pointed out was indeed the one that, after undergoing a very small change, causes PFHB.*

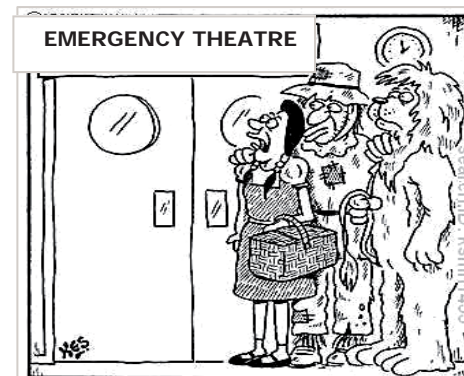
### KNOW YOUR PULSE IN 4 STEPS

- 1** To assess your resting pulse rate in your wrist, sit down for 5 minutes beforehand. Remember that any stimulants taken before the reading will affect the rate (such as caffeine or nicotine). You will need a watch or clock with a second hand.
- 2** Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent.
- 3** With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the stringy tendon attached to your thumb (as shown in the image). You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.
- 4** Count for 30 seconds and multiply by 2 to get your heart rate in beats per minute. If your heart rhythm is irregular, you should count for 1 minute and do not multiply.

**Record your pulse here**

Day	Result		Activity (e.g. after a run)
	am	pm	

A normal resting adult heart beats between 60 and 100 times per minute with some exceptions in a regular synchronized rhythm. An arrhythmia is an abnormal heart-beat which can be too fast, too slow or irregular, caused by the malfunctioning of the heart's electricity. Most arrhythmia are nuisance rhythms but some could be life threatening.



"I don't believe it. Five minutes after he gets the darn thing, he has an arrest!"

## CONTACT

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And where is this!?

Clue: The lake at B\_\_\_ on the N\_\_\_ island of S\_\_\_ emerged after a glacier melted.

## PACE POST



Lilian Jacobs  
Volunteer at UCT  
PACE exhibit



Lusan Luscombe  
and Juliet Rogan  
SAHA 2008

2010 EXCO:  
President: Prof A Okreglicki, Vice-President Prof Paul Brink, CEO Lusan Luscombe, Juliet Rogan, Althea Goosen, William Stranix, Prof Manie de Klerk, Franciska du Toit, Sydney Jacobs and Prof Rob Scott-Millar.

- 2010 EXCO: President: Prof A Okreglicki, Vice-President Prof Paul Brink, CEO Lusan Luscombe, Juliet Rogan, Althea Goosen, William Stranix, Prof Manie de Klerk, Franciska du Toit, Sydney Jacobs and Prof Rob Scott-Millar.
- New PACE Cell number: 082 6999 699
- Annual Membership now available
- First Zulu and Xhosa fact sheets!
- New Website design
- Website administrator appointed
- PACE Banner distributed
- Exhibits at Cardiology meetings



Dr Ronald M Jardine



A Special Interest Group of the South African Heart Association

The Cardiac Arrhythmia Society of Southern Africa is an organization of physicians, scientists and allied professionals throughout the subcontinent dedicated to the study of management of cardiac arrhythmia. Its vision is to improve the care of patients by promoting research, education and training and providing leadership towards optimal healthcare policies and standards. CASSA has been fully operational since 1998. The Society operates as an educational institution of a public character, providing specialized vocational training for medical specialists, doctors, nurses, paramedical and other health care workers, students, similar professionals and students to prepare them for work in the field of management of cardiac rhythm disturbances. CASSA further promotes collaboration between members and provide facilities for data collection on Arrhythmia and the use of ICD's in South Africa. The Society promotes research opportunities and participation in National and International trials in the sub-specialty. The Society represents the subspecialty to all relevant institutions and offers consensus on issues in the sub-specialty to professional societies, healthcare funders and industry in South Africa.

2009 was a busy year for CASSA and amongst its activities were a national symposium on Syncope, a GP Roadshow in the Western Cape, a slot on the program during the Medical Advisors Group Annual Conference and representation on the PMB clinical review committee of the Council of Medical Schemes.

CASSA is proud to be associated with sister organization PACE and this year saw the first ever CASSA/PACE joint meeting where treatment, care and support of patients suffering from arrhythmia and related diseases was discussed at length. CASSA recognizes the important role that PACE plays in educating the public and other role players in South Africa on the importance of knowing the signs and symptoms of arrhythmia. It also financially supports some of the literature distributed by PACE.

We are looking forward to an exciting year ahead during which PACE will be spearheading an awareness and educational drive on arrhythmia in 50 South African schools. Together, and through their individual activities, CASSA and PACE are shaping and changing the arrhythmia market in South Africa. CASSA will continue to support the PACE endeavors where we can in the future.

For further information on CASSA and its activities, visit [www.cassa.co.za](http://www.cassa.co.za).

Dr Ronald M Jardine

President: CASSA

**MEDTRONIC**

Medtronic is enormously proud to be associated with PACE. Throughout the previous few years we have seen this institution grow from its infancy into an organization that is truly making a difference in the lives of many South Africans affected by arrhythmias. We applaud the wonderful successes PACE has made during 2009 and look forward with anticipation to the fruition of the great PACE projects planned for 2010. Our association with the PACE organization is consistent with our own Medtronic mission of alleviating pain, restoring health, and extending life.



CareLink network enables remote monitoring

With the launch of Medtronic's CareLink Network in South Africa, remote medical monitoring will be taken to a new level within the local healthcare industry.

The Internet-based CareLink Network will enable patients with implantable cardioverter-defibrillators (ICDs) to transmit data from their devices directly to their physicians as part of a 'virtual check-up'. Patients simply hold a hand-held antenna over the implanted device, and information on how their hearts and ICDs are working is downloaded on to the Medtronic CareLink Monitor and transmitted through a phone line to a secure website.

Physicians can access this data - which is comparable to that gathered during an in-office check up - and make adjustments to the patient's medication or prescribe additional therapy, potentially without needing to see the patient in person. Recently-available ICDs are also compatible with Medtronic's CareLink Network with Conexus Wireless Telemetry, which transmits patient and device data automatically to physicians. These hands-free transmissions will be sent through if the patient's device detects a problem, such as an arrhythmia.

CareLink can also monitor and alert a patient's clinical condition regarding fluid buildup



William Stranix and Mike Howe-Ely

in the thoracic cavity. CareLink therefore reduces doctor visits, emergency hospital admissions, and eases the financial burden on patients and medical aids.

"We hope to significantly improve the quality of life of patients living with ICDs, who will be able to live with far more peace of mind, knowing that they can be in contact with their doctors wherever they are, says Mike Howe-Ely, regional director of Medtronic as CareLink also allows patients to stay connected to their physicians, even when travelling.

The Medtronic CareLink Network was first introduced in the US in 2002 and is also available in most Western European countries. In South Africa, CareLink will also soon be compatible with pacemakers and implantable cardiac monitors.

**SUPPORT GROUPS**

PACE Support Groups currently run in seven cities throughout the country. Each group meet four times annually to provide information and support to patients and their families.

"Living and understanding your device" was one of the interesting topics covered at support gatherings in Johannesburg and Cape Town. Danielle Fraide is a qualified ICU sister employed by Medtronic, responsible for technical support to patients with devices like pacemakers and implanted Cardiac Defibrillators. Danielle assisted with the first implant of an ICD in South Africa in 1990 and is very knowledgeable on the practicalities of living with an implanted device. She shared her expertise on the operation of devices, how they function when fibrillation occur and the affects of various medical procedures such as electroquetry and MRI scans.

Patients and their families were interested to discuss their emotional reactions and needs once diagnosed, with Sandra Hitchcock, a prominent Clinical Social Worker who specializes in trauma counseling. This presentation was followed by a lively discussion on the interaction of families once they have been exposed to a medical trauma. PACE will continue to provide information and re-assure patients and carers that there is help out there and other people that share their experiences.

**INFORMATION AND SUPPORT GROUP**

**CONTACTS**

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<b>Port Elizabeth</b>	<b>Cheldene Fick</b>	<b>041 4662741</b>
<b>Bloemfontein</b>	<b>Louise Cawood</b>	<b>084 606 3330</b>
<b>Durban</b>	<b>Juliet Rogan</b>	<b>084 205 9737</b>
<b>Johannesburg</b>	<b>Tony Michler</b>	<b>072 174 0538</b>
<b>Pretoria</b>	<b>Franciska du Toit</b>	<b>082 806 1599</b>



Knysna

**PACE PEOPLE**



Prof Valerie Corfield giving "DNA" lessons at Tygerberg



Barry Kock, Cheldene Fick Port Elizabeth PACE representative, Dr. , Dr Spilkin, Prof AO



Tygerberg Genetics Lesson



Annemarie Oosthuizen and Speaker Gill Davidson Cape Town



Speaker Danielle Fraide Johannesburg



Comrades 09



Speaker Sandra Hitchcock Tygerberg



Dr Nico vd Merwe Bloemfontein



Althea Goosen Tygerberg



PACE AGM 09

PACE once again participated in World Heart Rhythm Week and proudly became the first support organization in the world to establish arrhythmia awareness in pharmacies. We partnered with 100 Scriptnet and Dischem Pharmacies as well as PHD Distributors from 8-14 June 2009 and ran a campaign "Know Your Pulse".

- Each participating pharmacy received 5 red PACE/Know your Pulse T-shirts for the staff to wear to create awareness inside the pharmacy
- Each participating pharmacy got 2 WHRW posters which advertised this campaign at the pharmacy door as well as on the door of the clinic inside the pharmacy.
- The 'Know your Pulse' check cards were given to the dispensary staff as well as the front shop personnel and every person who entered the pharmacy during the period 8 – 26 June got one of these pamphlets. In many pharmacies, the clinic nurse would be available to assist members of the public to take their pulse.
- The 'Arrhythmia Checklists' were given to the Pharmacy Clinic Sisters to complete with all patients who came in for any 'cardiac related' test, e.g. BP, cholesterol etc.



Contact was made, either face-to-face or telephonically for the pharmacies outside of Gauteng, with both the head pharmacist as well as the clinic nurse of each and every one of these pharmacies and the feedback received was very exciting.

The majority LOVED this campaign and when the material we had printed lasted for longer than the proposed 8-14 June, all agreed to continue with the awareness drive.

We would like to thank the Arrhythmia Alliance UK for the sharing of their campaign material and wonderful ideas and including South Africa in their educational efforts.

PACE is looking forward to WHRW 2010 with much anticipation!



RESEARCH UPDATE



Prof Paul Brink

**HCM (Hypertrophic Cardiomyopathy)** HCM is a strongly inherited disease of thickening (hypertrophy) of heart muscle with a precipitous unforeseen death in a minority of carriers. Not all carriers display hypertrophy, yet may be of the minority with risk of premature death. The search for genetic factors that explains this variable profile and risk is ongoing at the Magic Lab at Biomedical Health Sciences and the Department of Medicine, Stellenbosch University by Prof Paul Brink and Prof Hanlie Moolman-Smook. Some of the causal inherited defects (mutations) occur in many different

families. With multiple cases sharing a mutation, this presents an opportunity to ask questions about a variability.

**LQTS (Long QT Syndrome)** This is an electrical disorder where the recovery after a heart beat is somewhat prolonged (hence the name) and is also strongly inherited. Collaboration between Stellenbosch University, Prof Paul Brink and Prof Peter Schwartz and Dr Lia Crotti from University of Pavia, Italy, and Prof Al George from Vanderbilt University, America, is ongoing. A number of causal mutations have been identified. One, representing about 40% of index cases (only first identified case is counted) of LQTS identified to date, is particularly common and could be traced to a couple that settled in the Southern Cape in the early 1700's.

**PFHB1 (Heartblock)**

This is a ventricular conduction disorder where slowed conduction may lead to complete heart block, a condition where the heart beat is much too slow to fulfill its pump function properly. The rogue gene has recently been found in a group of families that can trace its ancestry back to one Portuguese individual who landed on the shores of the Cape at the end of the 17<sup>th</sup> century.

**PFHB11**

Another form of heart block (called number11), as it has also been uniquely described in south Africa and reported simultaneously with PFHB1, is also being studied. Here the problem lies above the ventricles at the interface with the right atrium where the natural pacemaker of the heart resides.

MY PEARL HARBOR by Fiona Krisch

It's said that everyone has a moment in their life, a date or event, something that blasts familiar things out of existence. South Africans will never forget the tragedy of the Laingsburg floods in Jan 1981 or the Westdene Dam bus disaster, while the Americans had 9/11 in 2001 and Pearl Harbor on Dec 7 1941. Scroll forward to almost the same date, Dec 6 2005, and you'll find my Pearl Harbor. That's the day I found out that my daughter and I have LQTS — Long QT Syndrome.

*"Long QT - a genetic mutation - is described on the Mayo Clinic website as... a heart rhythm disorder that can potentially cause fast, chaotic heartbeats. The rapid heartbeats, caused by changes in the part of your heart that causes it to beat, may lead to fainting. In some cases, your heart's rhythm may beat so erratically that it can cause sudden death."*

**So why would I only find out, in my forties, that I had LQTS?**

Well, the fainting spells had originally been diagnosed as epilepsy, because my brain had shown seizure patterns that could loosely be ascribed to epilepsy. Problem is that it wasn't my brain, it was my heart. And my daughter had started getting fainting spells from about the age of five. Only once the real diagnosis was made did I find out that it's quite common for epilepsy to be the diagnosis for someone who really has Long QT. Sitting in the pediatric cardiologist's office, one warm December afternoon, I heard the horrible verdict that this wasn't just an inconvenience – as I had viewed it for most of my life – it was actually rather deadly, and unless

treated it could possibly kill me and my daughter one day. All it would take would be one of our usual triggers — shock, fright or intense exertion — and we could go into cardiac arrest. The heart would start to beat too fast (fibrillation) and unless it was stopped, that would be the end.

**How did LQTS show up?**

The doctor had picked up the prolonged QT interval on my daughter's ECG. He'd done his calculations and there it was. He then asked me to have an ECG right away, even though his was a pediatric practice — I'd been diagnosed with another heart condition two years earlier after blacking out while driving to work — because his questioning of my late father's medical history, and my grandmother's history as well pointed to a congenital problem. And so there it was, my Pearl Harbor, with fallout in every direction.

**How do we live with it?**

Well, my daughter and I take beta-blockers (Atenolol) which pace the heart to a specific rate - around 120b.p.m. in our case. This limits our activity levels so that we can't really exert ourselves to the point of fainting. It also blocks the effect of adrenalin on the heart so that any sudden fright or shock does not cause the rhythm to be disrupted to the degree that we go into ventricular fibrillation. We are also prohibited from actually doing anything strenuous – high-speed sports, like swimming or running, and I often joke that I used to say it would be amazing if a doctor could say I am banned from doing aerobics. Little did I know that's actually possible, and I was directed to do exactly that – no

aerobics or heavy gym sessions.

The swimming part is not easy in my daughter's case. Before the diagnosis she'd already shown signs of being a proper little fish in water, but now that she takes beta-blockers we have to watch her carefully. Swimming, in particular, can be a big trigger for LQTS. The limitations of beta-blockers have now made it so that she can't swim fast – an easy breaststroke is her maximum – but she still pushes boundaries by diving and doing crazy stunts in the pool. But we (her mom and dad) are always in attendance at the poolside, just in case. She is not allowed to swim at school, however. I just don't think that they fully grasp that we mean one-on-one attention is required when she's in water.

There's been mention made of getting an AED for my daughter – an automated external defibrillator – but they are expensive, and the stigma she might carry, having to lug around a "shock-box" everywhere, is not something I'd like her to be burdened with now. Neither she nor I have had any fainting episodes since our proper LQTS diagnosis, and that must mean that the beta-blocker management is working as it should.



Fiona and Eloise

Finally, I used to feel like I was treading on broken glass all the time, watching how we acted or what we did, but now it has settled into a way of LIFE.

MEDICAL SOCIETY MANAGEMENT



Franciska du Toit

**MSM - Medical Society Management**  
Since September 2008, MSM has been appointed to assist PACE with raising sponsorship and strategic business management of the organization. MSM - Medical Society Management - was formed to expand services rendered to Societies and other non-profit organisations. It is run by George Nel, an independent consultant to the Medical, Pharmaceutical and Device industry since 2003 and Franciska du Toit who joined MSM in July 2008 to focus on operational issues as well as expanding the financial viability of organisations that are contracted with MSM.

**MSM and PACE**

he past year has been an exciting one for MSM as it got to know the people and the networks involved with PACE. We developed a new understanding for patients and families affected by arrhythmia and got to work with interesting people both locally and abroad.

MSM assisted PACE in the organising and implementing of amongst others, the Know your Pulse Campaign during World Heart Rhythm Week. It also facilitated negotiations with Dischem in which the latter agreed to partner with PACE to become an information portal for patients and families affected by arrhythmia.

2010 promises to be a big year for MSM and PACE as it launches an awareness and educational program at 50 schools in South Africa. This program will run in conjunction with the FIFA Soccer World Cup as well as World Heart Rhythm Week 2010. Part of this project is a research arm in which Prof Paul Brink (University of Stellenbosch) will conduct a study to obtain the first ever truly South African data on the prevalence of arrhythmia in the young.

To get involved in any of the above projects or to find out more, contact Franciska du Toit on [franciska@cassa.co.za](mailto:franciska@cassa.co.za) or 0828061599

## TOOLS OF THE TRADE

*In the world of Cardiology, devices like pacemakers and defibrillators are to heart problems what the wheel has been to transport – life changing. And just because they work well doesn't mean the world of medical science isn't still improving on them every day.*



As opposed to a bypass – which is in actual fact a medical 'plumbing job' (making sure all the pipes – or arteries – are clean, working and supplying blood to the rest of the body), devices like pacemakers and defibrillators are the answer to electrical heart problems – where the messages sent to and from the heart regulating the pumping are abnormal. Prof AO Okreglicki explains that you can have "great blood supply, but no electrical signal to tell the heart when to pump." It's in these cases that the help of certain devices are called in.

**Keeping up the pace** Of all the devices used in Cardiology, the pacemaker is the oldest. This little intuitive tool – not much bigger than a Kruger Rand – is used when a heart is pumping too slow, or missing beats. "We all have natural pacemakers," says Prof Okreglicki. "But when their signals do not reach the heart, a pacemaker is needed. When the heart is pumping too slow, or when there are pauses in the beats, the device sends electrical signals to induce the heart-beat. So a pacemaker works only when needed and sends signals when it detects an abnormality in your heartbeat." Implanting a pacemaker is a relatively small operation, and the device is typically placed under the skin below of the collarbone, with a wire leading to the heart. Its battery can last from 6-9 years (depending on how much the device is used), but needs to be checked once a year. Once it expires or is flat, the whole device needs to be replaced.

**Split-second timing** "A modern defibrillator is in actual fact a very special pacemaker," says Prof Okreglicki of the device that is perhaps better known as two bats resembling paddles that are used in medical TV dramas like ER and Grey's Anatomy. "Now imagine those paddles as being much smaller, and as implants," he says. Miniaturised to the size of an MP3 player, defibrillators can now, like pacemakers, be implanted under the skin (also at the collarbone), and are called ICDs (implantable cardiovascular cardioverter defibrillators). They come standard with a built-in pacemaker, in the event of the heart beating too slow, or experiencing irregular pauses between beats. The American Heart Association sums defibrillation up as "the use of a device that gives an electric shock to the heart. This helps re-establish normal contraction rhythms in a heart having dangerous arrhythmia (a heart beat that is dangerously fast) or in cardiac-arrest."

"If a heart goes too slow, it doesn't work, but similarly, if it goes too fast, it can also be very dangerous," says Prof Okreglicki. "Going too fast means that the pumping action distributing blood through the body is not sufficient to stay alive. One minute's delay can cost a life." The 'paddles' have been around for 50 years and are applied on the skin on the chest, sending currents through the body in an attempt to jolt the heart back into beating normally. "This is all fine within a hospital situation," says Prof Okreglicki, "but what if the patient already has a damaged heart, and regularly have lethal electrical irritations of the heart that needs to be suppressed?" To some extent, this can be managed with medication, but it won't necessarily work every time, creating the need for a more sure-fire antidote.

If medical practitioners were told a hundred years ago that heart transplants, bypasses and even more ludicrous (at the time) – devices could be implanted to regulate heart beats, they probably would've been shocked. But given the huge strides that have been made, and are still being made, affordable devices that can prolong human life without any long-term difficulties doesn't seem so far-fetched anymore.



## COMRADES AND PACE!.....

What a day ! Being behind a refreshment station gives one a different insight of the organization involved in an event of this nature ! It certainly was a LONG day – for both the runners and organizers !



Each station had to collect the supplies prior to Comrades day – all 5 tons – and make sure they were delivered and ready on the day. This included 25 000 sachets of water, 5 000 sachets of Energade, 14 cases of coca cola, 12 boxes of bananas, 12 pockets of oranges, and many biscuits and chocolates. That is besides trying to keep sufficient ice and the drinks cool !

*It was a very early start to the day.* It didn't help that the police decided to close all the roads considerably earlier than we had been advised which made it more difficult and time consuming to collect the final items. But nevertheless, we managed to be ready for the cut off time.

We were very fortunate to find a number of volunteers (more than 50!) to assist for the event and they were all very eager to get started. The enthusiasm waned after the first few thousand

## MARATHON DES SABLES

Fundraising for a Patient Support Fund in what is reputed to be the toughest footrace in the world, Prof AO Okreglicki became the first South African to complete the gruelling Marathon des Sables in Morocco in April this year. This year the event was staged over 202 km to be completed in a period of 5 days. In addition to treacherous terrain and very challenging weather conditions, participants are required to carry their own food and gear - only water and rudimentary shelter is provided.



Torrential rains, floods and biting winds preceded the 24<sup>th</sup> Marathon des Sables. The 807 competitors that set off on the first stage of 33 km were faced with slippery mud just below an apparent dry surface and rocky hills of soft sand. Day 2 presented an even tougher terrain of vast stretches of rolling sand dunes and flat plains of gravel that appeared good to run on, but turned out to be similar to dry meringue which crushed under foot once the crust was penetrated.



The sand and soft running was enormously energy sapping. Day 3 and 4 comprised a total distance of 91 km to be completed against a constant strong, dehydrating headwind with heat and dust-storms. "The last 40 km turned out to be my favourite section: firstly a climb up a gorge of rocky mountain with magnificent vistas from the top just before sunset and then dunes and the vast Saharan plains strewn with rocks all made magical by the moonlight and a course marked by luminescent sticks – absolutely brilliant!" Says Prof AO, the President of PACE. He finished this stretch in a comfortable 13.5 hours. Having completed 4 days and 160 km in severe conditions, the athletes took the final stage and its tough terrain in their stride. Finishing 81<sup>st</sup> overall, AO described the Marathon des Sables as "much more than a run or a test of athletic skill. It is a rite of passage; a test of one's preparation, mind and endurance, all with the magic and romance of the sand."

## PATIENT SUPPORT FUND

AO's participation in the MDS as co-founder and President of PACE, will benefit many South Africans. He raised **R20 000!** which enabled PACE to establish a Patient Support Fund. Families and patients affected by ARRHYTHMIA, or survivors of sudden death, experience huge emotional challenges which need not be aggravated by impossible financial burdens. The patient support fund will thus assist suitable applicants with costs related to arrhythmia procedures, device implantation, treatment and care management. Fundraising for the FUND will be ongoing and a PACE TEAM of 15 athletes are already participating for PACE in the Half Ironman in January 2010!

*Prof AO, Lusan and THE CHEQUE!*



## .....COMRADES

runners though and many of them were swept of their feet when the 'buses' of runners came through. It proved to be very exhausting trying to feed and hydrate the runners as well as the volunteers !

The worst was yet to come. Trying to clean up after thousands of runners was also no joke ! It was impossible to imagine the litter that found it's way onto the roads, so it was another full time crew that tried to keep the roads clean and safe for the runners. To top it all, a few stations around us, including ourselves, ran out of water sachets ! Fortunately we managed to connect a hosepipe and man-

aged to 'water' a number of people. Although not ideal, it went a great way to assist very tired and thirsty runners.

I don't know who was more tired by the time the last 'runners' came through – the runners or us. And then we still had to clean ! It was an extremely exhausting task for a group as small as ours but it was certainly an experience of a lifetime and although it was hard work, it was enjoyed by everybody.

A special thanks to all those involved ! As for next year, it was a wonderful experience.....  
Juliet Rogan