Patient care represented at SASCRO/SASMO conference

2015 was the first year that People Living With Cancer had a stall at the big SASCRO/SASMO conference where the whole country’s oncologists, oncology nursing sisters, radiographers, physicists and oncology social workers gathered to learn about the latest research and developments in oncology worldwide.

There were six overseas speakers who gave details of the new chemotherapy regimens as well as advance radiotherapy techniques we can expect in the future. It is unbelievable how the cancer landscape has developed and how much more can be offered to cancer patients today!

The audience was made up of South African oncologists from the private and state sector and all of those who visited the stall were appreciative of the work done by PLWC and its associates and say that they look forward to referring patients and families for help.

The PLWC staff and buddies were focused on presenting all the organisation’s projects to visitors to the stall and each one received a packet of flyers and cards with the Toll free number on it. The very popular Photovoice project was showcased by exhibiting some banners with the stories of patients on them.

A few cancer buddies took turns to man the stall and it was wonderful to see Brian van Rheerde, Wadedah Jaffa, Jennifer Heunis and Martin Conley talking about our work to all and sundry. Janie du Plessis and her team took this opportunity to meet all the pharmaceutical company representative to introduce the work of PLWC and their projects and we hope to have more contact with these companies going forward.

Novartis also made it possible for PLWC to host a breakfast symposium on Patient Centredness, chaired by Linda Greeff. It was the first time that this topic was presented in a plenary at this Conference and we were lucky to have a very strong panel of speakers including Prof Hanna Simonds the new head of the Tygerberg hospital cancer unit, Dr Ernest Marais, Executive manager of Icon and, Ann Lamont an business consultant of Ernst and Young.

These speakers each highlighted the importance of working towards great patient centredness and also showed the commitment of people in positions of power to speak up about the need for change and to encourage all members of the multidisciplinary team to collaborate in developing strategies that will ensure improvement of the levels of patient centred care in the state and private oncology sector. Ms Ann Lamont shared details of a truly innovative project, that is currently being implemented in the Western Cape Department of Health, working towards greater patient centred care of patient’s in Western Cape hospitals.

The psychosocial support sessions at the Conference focused on the

Wings of Hope turns three!

Breast cancer support group, Wings of Hope, celebrated their third birthday in July in their usual exuberant style. More pics on page 4.

(continued on page 5)
A tattoo on the brain

In his brilliant 1993 satire “Et Tu, Babe,” Mark Leyner proposed a new concept in body art, which is the specialty of “visceral tattoos.” The narrator travels to Mexico where his chest is opened and the insinuation of a “guy surfing a wave of lava, wearing polka-dotted trunks,” is tattooed directly on his heart. The dye used shows up on CT scans and apparently women, especially x-ray technicians, love it. Superficially, a jest at those who indelibly paint their skin, Leynor’s parody is an allegory to the brutal invasiveness of healthcare. Going even further, we must understand that medicine often causes deep injury beyond that of the flesh. That injury is a tattoo of the mind.

When someone is treated for disease, their body is invaded. We open someone’s chest and replumb the vessels of the heart, remove and rebuild a breast, reconstruct a larynx, open the skull to remove a cancer, resect and reconnect inflamed bowel or simply use a scope to repair a knee. With these procedures, a person is healed, fixed and often cured. They are whole and pure again. Perhaps … but what about the mind?

Any invasion of the body that scars bone, muscle, and vessel, also scars the mind. An imprint on the spirit if you will, changing us at the deepest level. The psychological damage may be slight, just a little irritation, to be tucked away and never again considered. Sometimes the cut is so deep, so profound, that the person becomes forever a patient transformed, always wounded. The emotional ghost of the invasive act is a complex visceral picture stamped on conscious and unconscious mind, like the residual image of a brilliant flash bulb to the eye.

How can we predict how deep a wound may become, and how much it may transform? Is it the person or the act? It was just a minor procedure, a one day stay in the hospital, not really much pain, rapid recovery, she was back to work in two weeks, but somehow the wound buries deep into the core of a mind changed forever, a deep pain that never heals. Stage 1 melanoma ... take out the ovaries ... a near lethal aneurism ... no big deal ... really?

Such transformative wounds humiliate and confuse. How do you tell those that you love that though you are cured you are still in pain? How does one say, “I am different.” Should you not just be happy to be alive, and healthy? It is time to enjoy life and get back to the day-to-day! The world knows that you are well. Why does it not feel that way?

I have a patient who is born again healthy. His diverticulitis was treated with two surgeries, heart disease bypassed, prostate cancer in remission, hip replaced, cataracts removed, laryngeal polyps gone, hypertension controlled, hearing aids fitted and ulcers healed. He is perfect and has a fine prognosis. Nonetheless, he is a shell of the man who raised children, built a career, revered in sunsets and deeply loved his wife. A posttraumatic skeleton. Empty, depressed, nervous … the surgeon’s brand burned into his mind.

The critical lesson for doctors is the deep psychic affects of even successful therapy. Physicians must be aware that we invade not just the body, but also the psyche, leaving behind transformative images of pain, humiliation, and fear. This means choosing therapies carefully, educating well and giving care gently. It requires engaging with each patient after it is “over” to help him or her reconnect and heal. It means being aware that very long after the procedure, the invasion, wisps of suffering remain deep inside.

As family and friends of patients, we must also remember that healed and Healed are not the same thing. Just because the body is better, does not mean that the mind has followed. We need empathetic support and understanding long after the crisis has past. New trauma or stress can release demons, and we must all be aware and sensitive, for yesterday’s surgery is tomorrow’s pain.

Finally, as patients we must understand we have been changed. There is something brutal about invasive medical care, which may affect us deeply. We must be gentle with ourselves and realise healing is more than tissue deep. Healing is of the mind, and may in part take a lifetime. A wound hard to expect, a sore slow to mend. If we are not cautious, it can change our soul. A tattoo on the brain.
Why get involved in working with people living with cancer

by Elfrieda Strydom, Caregiver Buddy and National Cancer Buddies Coordinator

We all have a story as to why we get involved with cancer and why we choose to stay involved in the cancer scene. Some people choose to run away from fire, others are trained to run towards fire, and some are forced to run towards the fire because they do not have a choice and then they learn how to contain the fire by trial and error.

I am not sure where my story with cancer really starts. If I have to guess I think it started when I was 18 months old. My 8 year old brother died of a brain tumour. He had three operations but still died, six months after being diagnosed. So I grew up with the aftermath of that devastating loss. During the course of my life I lost several family members due to cancer, but none of them were so close to me.

I ended up becoming a social worker because I always knew I wanted to help people. In 2008 my opportunity came to become a medical social worker, working with people, living with HIV. My heart kept on yearning to work in the cancer field and in Sept 2011 I started my career as an oncology social worker. I soon discovered that a yearning to work with cancer patient was not enough, you need to have knowledge. I was fortunate to have somebody like Linda Greeff in my life to help me develop my knowledge of cancer and working with cancer patients. Three months after starting working in the cancer field, I started with my practical development when my dad disclosed that he has symptoms which fit the colon cancer scenario. My dad was 86 years old, at the time and living in a retirement village in Ladysmith, KwaZulu Natal. He was a Transmed patient and thus had to have his treatment in the Government sector. My dad was convinced he would be able to do the journey on his own and from his home town. But after two days sitting in the queue waiting to see the doctor for a referral to Greys Hospital, Pietermaritzburg, and not hearing when they call his number, he was ready to come to Bloemfontein in order for me to help him. And so my journey with my dad and his colon cancer started.

I knew it was going to have an impact on my family, but I thought it was going to be for six months and then he will be gone, so it is not going to be that big of a sacrifice. But that is the thing with cancer, you know it was going to be for six months and then he will be gone, so it is not going to be that big of a sacrifice. But that is the thing with cancer, you get all kinds of curved balls aimed at you. My dad passed away on 8 Dec 2013 after nearly two years living with his colon cancer.

Looking back I do not know how I got through it. I just know that the last two months of my dad’s life, I started praying that if God is not going to take my dad, then He must please take me, because I could no longer tolerate the suffering my dad and my family had experienced. I learned a lot of valuable lessons, which I think has helped me a great deal in understanding what the cancer patients and their families go through. I have certainly learned a lot about how strong one can be, even I you do not consider yourself to be like that. I had to fight many battles with the medical staff and the medical aid. During my father’s treatment, he received two cycles of chemo, radiation therapy, had to get a stoma and nearly died of an infection which resulted in him receiving a super pubic catheter. I have learned how difficult it can be to navigate your way through the medical mine field. My dad was treated in an academic setup, with the result that every time he was seen at the clinic, he saw another intern. They wanted to perform the same tests over and over again, the surgeon after giving the results that my dad had cancer of the sigmoid just wanted to do an operation the following day. When I said we need time to think or to talk to another professional they got upset with us. I felt that some of the medical team members did not have any compassion for their patient.

In order to protect my father and to make sure that he receive the correct treatment for his age and cancer, I had become a person I did not know. One who is always alert, and ready to fight for him to obtain the medication or treatment he was supposed to receive.

I had to take over my father’s financial affairs, had to pack up his flat when he realised he will not be able to go back there. In my own family I became isolated, detached from them and my husband took over responsibilities which I would always perform. Taking care of a cancer patient, is a full time job. Navigating that with a full time job is very challenging.

My friends did not know how to support me, because

(continued on page 4)
Above: A great party was enjoyed by all attending the Third Birthday of the Wings of Hope Support Group on 18 July 2015. Entertainers, prizes galore, good food and singing and dancing was the order of the day.

Wings of Hope in action

One Saturday in August, Wings held a very successful debriefing meeting for their supporters. This is essential for people who spend their time helping patients through their cancer journey. Thanks go to Dr. Lynn Farrow, psychologist, who chaired and guided this difficult process.

But when Wings has time to relax, they really party as you can see.

they had never been on this type of journey. This makes you feel more isolated. I felt that I had so many responsibilities and that so much of how my dad’s treatment journey went depended upon my management. Sometimes I would wish somebody else could take over some of the responsibilities and decisions that had to be made.

At night time when I got into bed, I would not be able to sleep, my whole body would be trembling, and my mind racing as to how to make all the pieces fit and come together. But each morning would bring its own challenges. It was difficult to see how my dad changed from a loving friendly person, to a frail, sad and depressed person, having to deal with so many losses, that it was crippling him. After receiving the super pubic catheter he had nerve damage which cause him to have constant pain and discomfort. Nearing his end, the interval between “crisis’s” and “fall back’s” became closer, and there was no time to recover from the one to the other crisis.

It was unbearable to see how my kids had difficulty in dealing with “oupa’s” deteriorating condition. Their anger, their sadness and still praying for him to get better. I felt guilty towards my kids and husband, and even my employer because I realised my head was not in the game anymore.

When I was with my dad, I felt guilty and wished I was with my family, and when I was with them I felt guilty that I was not with my dad.

I got to know the dark inner side of me, the one I did not know I have!

After my dad’s passing I started my journey back to my “old” life. It was hard, really hard, because I came to realise, I was no longer part of the inner circle of my family, I was sad for my dad’s loss, I was angry that he had to suffer, and came to realise, there is no “old” life, there is only “new” life. I have changed, and I have lost myself, my identity, my family, and some friends, along the way - 20 months later, I can say the journey to healing was as difficult as the journey with my dad and cancer. But, it was a privilege to know my dad did not have to do it on his own, I have no regrets towards my father, because we have lived and loved till the end.

So why am I still in the cancer business? The following quote says it all: “To companion the suffering is an act of courage. The sufferer has to be in his painful situation, the companion chooses to be. It is a breath-taking and profound act of love to enter into someone else’s darkness to give your vulnerability to them and to receive theirs, never knowing exactly what it is going to look like or feel like. It is holy ground and you and the sufferer are pilgrims on a journey together. You can be a witness and a validation, you can be a beacon of hope, you may just be the reason the sufferer is able to bear their burden for one more day” - Jefri Franks.

As we choose to stay involved with the journey of cancer, and we often face hardship it is also a very rewarding journey, knowing you have made a difference, you have a purpose in life.

Keep on caring...
Dealing with death, dying and grief - a workshop that highlighted the importance of support staff being aware of their own emotional wellbeing when caring for cancer patients and their families. This session was presented by Dr Marc Lipshitz, a clinical psychologist from Cape Town.

Dr Henriette Steyn presented a great talk illustrating the value of having support groups for laryngectomy patients at Tygerberg hospital and the video footage she shared was inspirational.

A masters level oncology physiotherapist spoke about the importance of post cancer treatment late side effect management and it highlighted the fact that we still have so much to put in place to really provide comprehensive cancer care to patients.

A radiographer from Gauteng presented qualitative research on the needs of coal miners being treated in a practice in Rustenburg. This talk showcased their complex needs and the importance of being culturally sensitive when we provide services to patients and to individuals from different cultural backgrounds. The psychosocial circumstances are complex and impact their experience of their cancer treatment and the team should be sensitive to their needs and ensure that they understand the treatment they are receiving and the impact of this on their future lives.

One must feel inspired by the developments in oncology currently around the world but we are also sensitised by the fact that we need to work harder to make patients and families feel safe in our care by providing supportive services that will ensure that patients’ needs are met and that their emotional wellbeing is considered as part of the cancer treatment trajectory of care.

The role of cancer NGO’s in the care of cancer patients was clearly showcased and we now have to keep developing services that will truly reach more people in need of care during their cancer journey.

A big thank you to the SACRO/SASMO management team and Rhyno Kriek the conference organiser for supporting PLWC and our participation in this Conference – it was an honour and a privilege to participate.

How spiritual beliefs relate to cancer patients’ well-being

Research reveals that most individuals with cancer have religious and spiritual beliefs, or derive comfort from religious and spiritual experiences. But what impact does this have on patients’ health? Recent analyses of all published studies on the topic—which included more than 44,000 patients—shed new light on the associations of religion and spirituality with cancer patients’ mental, social, and physical wellbeing. Published early online in CANCER, a peer-reviewed journal of the American Cancer Society, the analyses indicate that religion and spirituality have significant associations with patients’ health, but there was wide variability among studies regarding how different dimensions of religion and spirituality relate to different aspects of health.

In the first analysis, investigators focused on physical health. Patients reporting greater overall religiousness and spirituality also reported better physical health, greater ability to perform their usual daily tasks, and fewer physical symptoms of cancer and treatment. “Spiritual well-being was, unsurprisingly, associated with less anxiety, depression, or distress,” said lead author John Salsman, PhD, who conducted the research while at Northwestern University’s Feinberg School of Medicine in Chicago, but is now at Wake Forest School of Medicine in Winston-Salem. “Also, greater levels of spiritual distress and a sense of disconnectedness with God or a religious community was associated with greater psychological distress or poorer emotional well-being.”

The third analysis pertained to social health, or patients’ capacity to retain social roles and relationships in the face of illness. Religion and spirituality, as well as each of its dimensions, had modest but reliable links with social health. “When we took a closer look, we found that patients with stronger spiritual well-being, more benign images of God (such as perceptions of a benevolent rather than an angry or distant God), or stronger beliefs (such as convictions that a personal God can be called upon for assistance) reported better social health,” said lead author Allen Sherman, PhD, of the University of Arkansas for Medical Sciences in Little Rock. “In contrast, those who struggled with their faith fared more poorly.”

Patents threaten access to vital medicine

by Marcus Low, Catherine Tomlinson, Julia Hill and Umunyana Rugege

One of the cornerstones of an effective intellectual property (IP) system is the examination of patent applications. After all, before approving an application, the “invention” in question must meet the legal criteria for what deserves to be granted a patent. Unless you believe monopolies are unreservedly beneficial for free trade and society more generally, you would agree that it is illogical to grant a 20-year patent without checking whether the “invention” is new and innovative.

Under the current “depository system” SA does not examine patent applications. If the paperwork is filed correctly, the patent is granted.

Our patent system has thus allowed high numbers of unwarranted patent monopolies or extensions of existing monopolies, which limits and delays competition in our local markets. Granting undeserved patents has particularly serious implications for access to medicines, since companies may file multiple patents on medicines over time to delay the introduction of generic competitors. Low-quality patents are vulnerable to challenge in court but in reality this is not a true safeguard as patent litigation is expensive, lengthy, uncertain and infrequent.

The good news is that the Companies and Intellectual Property Commission (CIPC) has announced plans to replace the depository system with an examination system. The feasibility and effect of such a system has been the focus of discussions and debates among policy makers, industrial players, academics and civil society. SA should not, however, fall into the trap of thinking that the complexity of patent examination and resistance to change are excuses for inaction.

One valid concern is the requirement for highly skilled human resources to conduct patent examination. The best way to deal with this challenge is to phase in the system’s introduction. CIPC could start by introducing patent examination in sectors such as pharmaceuticals, where the public interest provides a strong reason to prevent poor-quality patents from being granted. As human resource capacity is developed, examination can be expanded to additional sectors.

Another proposed solution to human resource constraints relies on collaboration with other countries’ patents offices. Improving information flow between IP offices can expedite decision-making processes.

However, it is vitally important that the ultimate decision on patent applications is made by SA, to be in line with national legislation and developmental objectives.

The cost of running a patent examination system has been another point of contention. Resources required, however, could be financed by restructuring patent application and maintenance fees, which are 20-30 times lower than in other developing countries. The Indian Patents Office generates a significant surplus over operating costs through its fee structure. There is no reason SA cannot do the same.

Higher patent application fees will also help discourage frivolous applications. Altering fee structures need not make application costs unaffordable for small businesses or local applicants.

Other countries, including the US, charge different filing fees, depending on the size of the entity.

Make no mistake, SA will not establish a fully functional patent examination system overnight. Yet, the longer we wait, the greater the financial burden of affording life-saving medicines will become.

This reality means the CIPC must, as a matter of urgency, start training patent examiners and building the structures needed to facilitate patent examination. Refusing to start this journey would be a deeply negative form of defeatism, and a failure to take the necessary steps to improve access to medicines.

If you have a patient story, or other issue to discuss that you would like to keep private or confidential, please contact researcher@joburg.msf.org and julia.hill@joburg.msf.org.

*Bow is with the Treatment Action Campaign; Tomlinson and Hill are with Doctors Without Borders SA and Rugege is with SECTION27.

Buddies for Life now online

The popular Buddies for Life lifestyle magazine for breast cancer patients and survivors is now out. It is also now available on line at http://www.buddiesforlife.co.za and many of the excellent articles in the magazine are of interest to other cancer patients.

LET’S TALK ABOUT CANCER!

Join us at a CanSurvive Cancer Support Group meeting
- have a cup of tea/coffee, a chat with other patients and survivors and listen to an interesting and informative talk.

Upcoming meetings:
HEAD and NECK Group - 3 September at Rehab Matters, Rivonia
PARKTOWN - 12 September, Hazeldene Hall (opp. Netcare Park Lane Hospital) 09:00

Enquiries:
Bernice 083 444 5182 or bernicelass@outlook.com
Chris 083 640 4949 or cansurvive@icon.co.za
www.cansurvive.co.za

The Groups are run in association with the Johannesburg Branch of Cancer Buddies and is hosted by Netcare. The Group is open to any survivor, patient or caregiver. No charge is made.
Explaining the head and neck cancer patients’ perspective

In 2014 the International Federation of Head and Neck Oncologic Societies declared 27 July as World Head & Neck Cancer Day. This year it was commemorated in 53 countries worldwide.

WITS Medical School ran a two day conference for specialists, radiation oncologists, head & neck surgeons, registrars, medical physicists, medical officers, radiation therapists and oncology nurses. The aim of this programme was to discuss awareness, risk factors, cessation, prevention, public education, screening, early diagnosis, physician education, outcomes and survivorship.

In keeping with the international trend to involve patients, CanSurvive Rivonia was invited to present the patient’s perspective. They had a panel of three, Kevin Lovell, Ian Lucas and Gareth Nefdt, who shared their stories with the medical professionals. Each told of the many challenges created by treatment of their cancer. Most of the problems are permanent, and are not over once treatment is complete. For example, surgery, radiation and chemotherapy, in any combination, cause loss of ability to eat. Losing 20% of one’s body weight is the norm. After surgery, but before radiation, patients have to have some, or all, of their teeth removed, as radiation permanently disrupts blood supply to the jaw. Patients lose jaw opening range, and need ongoing physiotherapy that needs to start during radiation. Most have severely diminished speech capacity initially, often needing speech therapy. Some lose the ability to swallow, and need intense swallow therapy involving electrical stimulation. And of course it is a visible cancer. Surgery causes disfigurement which is visible to all.

Kim Lucas spoke about the value of the support group which consists of people that have had any form of cancer in the head or neck area. The group has members ranging from newly diagnosed patients, all the way to 19 years down the treatment and recovery path. People that have walked this road already, are able to help and support those who are just beginning treatment.

A very strong message of the necessity for education, early detection and patient-on-patient support, was imparted to the attendees.

The CanSurvive Head and Neck Support Group is for anyone who has had trauma to the head or neck – not only cancer related – although that applies to the vast majority.

The informal and supportive meetings are usually held on the first Thursday of each month at Rehab Matters, 1 De la Rey Rd. Rivonia from 18h00 to 20h00. There is also a Facebook group: South African Head and Neck Support Group

For more information, contact Kim Lucas, on 082 880 1218 or e-mail: lct@global.co.za.

Manny de Freitas Foundation seeks alternative cancer solutions

The second Manny de Freitas Foundation (MdFF) Men’s event which took place on Monday, 27 July 2015 proved to be even more successful than the first such event which took place last month. This event, which took for form of a dinner wine tasting, was enjoyed by all.

This event was partnered with Zevenwacht Wines. The various courses of the meal was wine-paired with different wines from that wine farm. A silent auction was held where funds were raised for MdFF cancer projects. MdFF founder, Manny de Freitas said that the Foundation aims to partner with roleplayers who will work to look at alternative treatments into cancer solutions.

“It simply makes no sense that more cancer solutions are found yet more than ever people are being infected and affected by cancer,” de Freitas explained. De Freitas said that more needs to be done into other cancer solutions as what is currently done is simply not good enough.

Brain cancer patients and caregivers - can you help?

We have received a request for help from a British company directed at brain cancer patients who are Afrikaans speaking. She writes:

I work for PharmaQuest Ltd. which is a medical translation company specialising in Quality of Life and Patient Reported Outcome (PRO) questionnaires.

We are running a project in South Africa that involves the translation into Afrikaans of a quality of life questionnaire on brain cancer (called the BN20).

We are looking for Afrikaans speakers who have brain cancer or have had a brain tumour in the past 3 years to take part in interviews to give us their opinions on a short questionnaire about their experience of brain tumours. The questionnaire will eventually be used in multi-national trials so our aim is to assess whether the translation accurately reflects the meaning of the original questionnaire and to ensure it is well-phrased and understandable. We will ask respondents whether the text is clear for them, what they understand each question to mean and if there is anything which is difficult to understand.

Our in-country investigator would meet the respondents at a convenient time and place, and respondents would be reimbursed for their time.

We are looking for respondents as soon as possible, so I would be grateful if you could put a note in your social media or via email. It would also be great if you could also include it in your e-newsletter.

Rachel Neal, BA, Translation Coordinator, PharmaQuest Ltd

You can contact Rachel at rachel.neal@pharmaquest-ltd.com. The company’s website is www.pharmaquest-ltd.com

HAVE YOU GOT YOUR PINK RIBBONS YET FOR BREAST CANCER MONTH (October)?

Don’t be the odd one out, get your Breast Cancer Awareness ribbons today, whether it is for you, for a friend, family member or for your company. Get yours today.

Go onto the PinkDrive website or email chantelle@pinkdrive.co.za and avoid the mad PinkRush.

There is a variety of ribbons for you to get!
You’re the boss: manage your disease

You can manage your disease better than anyone else can. Chronic diseases such as heart disease, cancer, asthma, type II diabetes—you may not be able to cure them, but you can manage them to live an energetic, extraordinary life filled with creativity and enjoyment.

How do you manage your disease?

Start with learning everything you can about the disease. Explore the internet top five searches. Trust yourself, you will be able to read sources that will help you. Learn the causes and learn how the disease is diagnosed—what tests and x-rays are helpful. Is a biopsy needed? Learn the treatment options. There are always options—the natural course of the disease without treatment, medical treatment, surgical treatment, and complimentary treatments. Monitor the progress—is it improving, staying the same, worsening. Often staying the same is good enough, as this is managing the disease and will not interfere with your life. If worsening, try another option. Finally, create a healing environment. This is where the mind is a powerful. You can be healed without being cured. It’s in the mind.

What do you need to know about diagnosing your disease?

You may think that diagnosing disease is the doctor’s job. This is true, yet it is helpful for you to learn about the diagnostic process because you’re going to be asked to decide which tests to have. Some are simple, a blood test or urine test, while others such as special x-ray tests and especially tissue biopsies are complex and have potential adverse reactions. So, learn about potential causes of disease and the diagnostic process. Importantly, ask your doctor the reason for the test, what happens if you don’t do the test, the chance of making a diagnosis, the risks of the test, and finally alternative options.

Find out the treatment options

There are always options. Ask your doctor what happens if you don’t do anything. What is the natural history of the disease process? This will help you several ways. First, the process may resolve over time. Second, you will have something to monitor to determine if the treatment plan is working. Third, it may be a rapid deadly outcome and you will have intense decisions to make. After this, ask about the medical treatment options. What medicines will be used? What is the typical outcome with these medicines? What are the adverse reactions of the medicines? You may need to know surgical options. What is the operation? What are the chances of success? What are the risks? Ask the same questions about chemotherapy and radiation treatments. When you find out the answers, you will be able to weigh the benefits and the risks to make a decision that is best for you.

Monitor your disease

Now that you have a treatment plan, it is helpful to monitor the progress. This can be simple by keeping track on your iPhone or computer, or developing an elaborate computer graph. Use the 48-hour rule. If the process is improved in 48 hours, continue the plan. If the process is unchanged, give another 48 hours and re-evaluate. If worse in 48 hours, contact your physician and maybe continue the plan or change the plan, depending on severity. If there is dramatic worsening, call 911 or go to the emergency room.

How do you heal?

Healing is a state of mind. You can be healed despite having a chronic disease. I’m reminded of the professional piano player who was blind and emaciated from AIDS, yet as he was sitting at the piano, he told the interviewer he was at peace and healed. He died the next day. You can learn how to heal. There are several do n’ts: Do not dwell on your disease. Do not complain to others. Do not let the disease take over your life. Follow what has been discussed: Learn about the disease, know you have chosen the best diagnostic studies and treatment options for you, and monitor the process. Develop a positive attitude toward the management plan. This will give you a feeling of control and being in charge of the disease. Next, you need eight hours of sleep, one hour of exercise, and eat the right foods in the right amount including lean protein, omega-3 fatty acids, and slow-burn carbohydrates. Use the power of your mind, spend alpha brainwave time through meditation. Have compassion for yourself and the organ system involved. Use visualization of healing the process. Develop relaxation techniques through belly breathing and yoga breathing (equal breath in and equal breath out). Manage stress through these techniques.

Take action

Learn about your disease, know the diagnostic process, understand the treatment options, monitor the disease, and create an environment for healing. You are in charge. You can manage your disease better than anyone else. Your chances of success are unlimited.

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Cancer Support and Information Group

2 September 2015 10:00 – 12:00

Our guest speaker is Dr Daan Stutting

and his subject is Definition of Spirituality

How Spirituality can help in Cancer Care

The venue is the Boardroom at GVI Outeniqua Oncology, 3 Gloucester Avenue, George

To book your seat contact Engela on 044 884 0806 or email engela.vandermerwe@cancercare.co.za

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Dates to diarise

**August 2015**

22  Cell C Shark vs Emirates Lions in aid of breast cancer (PinkDrive)
27  Reach for Recovery, Cape Peninsula 10:00. Does deodorant cause breast cancer?

**September 2015**

3   CanSurvive Head and Neck Support Group, at Rehab Matters, 1 De la Rey Rd. Rivonia at 18h00
5   Bosom Buddies, Hazeldene Hall, Parktown, 09:30 for 10h00
5   Can-Sir & Can-Sir malecare, Prostate Awareness Breakfast 9:30 (Venue TBA)
6   Netcare CanSurvive Walk for Cancer and Holistic Health Fair, Lonehill Park, Johannesburg 08:00
8   Reach for Recovery, Roodepoort Centre for the Aged, Robinson Street, Horizon 14h00
12  CanSurvive Cancer Support Group, Hazeldene Hall, Parktown 9:00
12  Wings of Hope, German International School, Parktown, 09:30 for 10:00
15  Prostate & Male Cancer Support Group, Auditorium, Constantiaberg MediClinic, 18:00
16  Reach For Recovery, Johannesburg, venue to be annouced 13:30
17  Reach for Recovery, Cape Peninsula 10:00. Reconstruction options after surgery

**October 2015**

1   CanSurvive Head and Neck Support Group, at Rehab Matters, 1 De la Rey Rd. Rivonia at 18h00
3   Bosom Buddies, Hazeldene Hall, Parktown, 09:30 for 10h00
10  CanSurvive Cancer Support Group, Hazeldene Hall, Parktown 9:00
20  Prostate & Male Cancer Support Group, Auditorium, Constantiaberg MediClinic, 18:00
24  Wings of Hope, German International School, Parktown, 09:30 for 10:00
29  Reach for Recovery, Cape Peninsula 10:00. Pink Surprise

**November 2015**

5   CanSurvive Head and Neck Support Group, at Rehab Matters, 1 De la Rey Rd. Rivonia at 18h00
10  Reach for Recovery, Roodepoort Centre for the Aged, Robinson Street, Horizon 14h00
14  CanSurvive Cancer Support Group Celebration of Life, Sunnyside Park Hotel, Parktown 9:00
17  Prostate & Male Cancer Support Group, Auditorium, Constantiaberg MediClinic, 18:00
18  Reach For Recovery, Johannesburg, 19 St John Road, Houghton 13:30

**CONTACT DETAILS**

- **Cancer Buddies Johannesburg branch, and CanSurvive Cancer Support Groups - Parktown and Waterfall:** Chris Olivier 083 640 4949, cansurvive@icon.co.za
- **CanSurvive Head and Neck Support Group, Rivonia, Johannesburg:** Contact Kim Lucas 0828801218 or lct@global.co.za
- **Cancer Buddies/People Living with Cancer, Cape Town:** 076 775 6099, info@plwc.org.za, www.plwc.org.za
- **GVI Oncology /Cancer Buddies, Rondebosch Medical Centre Support Group:** Contact: Linda Greeff 0825513310 linda.greeff@cancerbuddies.org.za
- **GVI Cape Gate Support group:** 10h00-12h00 in the Boardroom, Cape Gate Oncology Centre.
  Contact: Caron Caron Majewski, 021 9443800
- **GVI Oncology Somerset West group for advanced and metastatic cancers. Contact person: Nicole Andrews 0218512255**
- **Cancer.vive, Frieda Henning 082 335 4912, info@cancervive.co.za**
- **Can-Sir, 021 761 6070, Ismail-Ian Fife, ismailianf@can-sir.org.za Support Group:** 076 775 6099.
- **Prostate & Male Cancer Support Action Group, MediClinic Constantiaberg. Contact Can-Sir: 079 315 8627 or Linda Greeff 0825513310 linda.greeff@cancerbuddies.org.za**
- **Wings of Hope Breast Cancer Support Group 011 432 8891, info@wingsofhope.co.za**
- **PinkDrive: www.pinkdrive.co.za, Johannesburg: febe@pinkdrive.co.za, 011 998 8022**
- **Prostate & Male Cancer Support Action Group, MediClinic Constantiaberg. Contact Can-Sir: 079 315 8627 or Linda Greeff 0825513310 linda.greeff@cancerbuddies.org.za**
- **Wings of Hope Breast Cancer Support Group 011 432 8891, info@wingsofhope.co.za**
- **PinkDrive: www.pinkdrive.co.za, Johannesburg: febe@pinkdrive.co.za, 011 998 8022**
- **Cape Town: Adeliah Jacobs 021 697 5650**
- **Durban: Liz Book 074 837 7836, Janice Benecke 082 557 3079**
- **Bosom Buddies: 011 482 9492 or 0860 283 343, Netcare Rehab Hospital, Milpark. www.bosombuddies.org.za.**
- **CANSA National Office: Toll-free 0800 226622**
- **CANSA Johannesburg Central: 011 648 0990, 19 St John Road, Houghton, www.cansa.org.za**
- **CANSA Pretoria: Contact Miemie du Plessis 012 361 4132 or 082 468 1521; Sr Ros Lorentz 012 329 3036 or 082 578 0578**
- **Reach for Recovery (R4R) : Johannesburg Group, 011 869 1499.**
- **Reach for Recovery (R4R) : West Rand Group. Contact Sandra on 011 953 3188 or 078 848 7343.**
- **Reach for Recovery (R4R) Pretoria Group: 082 212 9933**
- **Reach for recovery, Cape Peninsula, 021 689 5347 or 0833061941**
- **CANSA offices at 37A Main Road, MOWBRAY starting at 10:00**
- **Reach for Recovery: Durban, Marika Wade, 072 248 0008, swade@telkomsa.net**
- **Reach for Recovery: Harare, Zimbabwe contact 707659.**
- **Breast Best Friend Zimbabwe, e-mail bbfzim@gmail.com**
- **Cancer Centre - Harare: 60 Livingstone Avenue, Harare**
  Tel: 707673 / 705522 / 707444 Fax: 732676 E-mail: cancer@mweb.co.zw www.cancerhre.co.zw
**News in brief**

**ASCO 2015**

The 2015 annual meeting of the American Society of Clinical Oncology (ASCO) featured many important studies that may affect how primary care physicians (PCPs) treat their patients at high risk for cancer, those with cancer, and those who have survived a cancer diagnosis.

Medscape asked Larissa Nekhlyudov, MD, MPH, an associate professor of population medicine at Harvard Medical School, to provide takeaways on how these study results may influence primary care physicians’ practice. Her main message from these studies was “that lifestyle habits and physical activity after a cancer diagnosis matters. These studies continue to shift the paradigm in oncology follow-up. The concept that being more active and losing weight is good was not in the lingo of most oncologists or the cancer community. But now, more and more research is showing that of physical activity has beneficial effects on quality of life among cancer patients.

“Primary care doctors should continue to encourage cancer patients to maintain healthy lifestyles, but we also need our oncology colleagues to reinforce that message. When an oncologist says that exercise will help you feel better and may reduce your likelihood of having a recurrence or dying of cancer, patients may hear that louder.”


**Long-term ovarian cancer survival higher than thought**

Combining data collected on thousands of California ovarian cancer patients, UC Davis researchers have determined that almost one-third survived at least 10 years after diagnosis.

The unprecedented findings upend the notion that women diagnosed with cancer of the ovary always face a poor chance of survival. In fact, while the study confirmed earlier findings on characteristics associated with ovarian cancer survival - younger age, earlier stage and lower grade tumours at diagnosis - it also identified a surprising number of long-term survivors who didn’t meet those criteria.

As expected, the study found that the majority of the long-term survivors were younger, had early-stage disease when they were diagnosed and their tumours were of a lower-risk tissue type. What struck the researchers was that of the 3,582 long-term survivors, 954 of them had been considered to be at high risk of dying from their disease, either because of their tumour stage, grade or older age at diagnosis.

“This information is important for patient counseling,” says study co-author Gary Leiserowitz, a professor of gynaecologic oncology and interim chair of the UC Davis Department of Obstetrics and Gynaecology. “Many patients and physicians know that ovarian cancer is a dangerous cancer, but they don’t realise that there is significant biological variability among patients. It’s not a uniformly fatal prognosis.”

“This is an exploratory study to figure out who has survived,” Leiserowitz adds. “We can now go back and look at tumour tissue to do a comparison between long- and short-term survivors to see if there is a genetic basis for that.”

[http://tinyurl.com/qxutce2](http://tinyurl.com/qxutce2)

**Topical gel safe, effective treatment for skin T Cell Lymphoma**

Results of a phase one trial show that an investigational topical drug, resiquimod gel, causes regression of both treated and untreated tumour lesions and may completely remove cancerous cells from both sites in patients with early stage cutaneous T cell lymphoma (CTCL) – a rare type of non-Hodgkin lymphoma that affects the skin. Currently, there is no cure for CTCL aside from a bone marrow transplant. However, the new study from researchers at the Perelman School of Medicine at the University of Pennsylvania, shows that the topical gel can eliminate malignant T cells, leading to diminished lesions.

The study was published online in August in the journal Blood.

**Pelvic Radiation Disease Association**

In June the first Clinical Trials conference for Supportive Care in Cancer Research was held in the UK. The day was of particular interest as Dr John Staffurth spoke on ‘How advances in radiotherapy can reduce late pelvic effects’ and there was also an excellent talk on ‘Assessing and meeting the needs of people living with and beyond cancer’. Dr Staffurth said that of those who experience long term effects 90% will experience a permanent change in bowel movement and of these 40% will suffer moderate to severe problems. He then went on in more detail about current forms of radiotherapy and the different problems arising, followed by some suggestions on how to alleviate post treatment problems.

You can contact the Association at www.prda.org.uk and on Facebook [https://www.facebook.com/pages/Pelvic-Radiation-Disease-Association/362315120452162?sk=info&tab=page_info](https://www.facebook.com/pages/Pelvic-Radiation-Disease-Association/362315120452162?sk=info&tab=page_info)

**Prostate cancer has five different types**

In a recent study researchers claim to have found that there are five genetically distinct types of prostate cancer, and suggest different treatments could be targeted to each patient.

In the study published in EBioMedicine, researchers said analysis using their new discoveries is better at predicting how cancer will progress than tests doctors already use, including those for Gleason score and PSA, or prostate specific antigen, levels.

“This research could be game-changing if the results hold up in larger clinical trials and could give us better information to guide each man’s treatment - even helping us to choose between treatments for
The treatment uses a chemical to block an RNA molecule that’s suppressing the development of ulcerative colitis, a disease that causes an increased risk of developing colon cancer, but doctors still are unsure why.

Instead of slight differences between tumours, researchers found five distinct types of prostate cancer based on 100 genes which indicated chances of progression with more accuracy than the commonly used PSA and Gleason score tests. Previous research had shown six of the genes were associated with prostate cancer, however researchers wrote in the study that the other 94 had not been linked to the disease until now.

MIND your diet

Eating a group of specific foods known as the MIND diet may slow cognitive decline among aging adults, even when the person is not at risk of developing Alzheimer’s disease, according to researchers at Rush University Medical Centre. This finding is in addition to a previous study by the research team that found that the MIND diet may reduce a person’s risk in developing Alzheimer’s disease.

The MIND diet has 15 dietary components, including 10 “brain-healthy food groups” and five unhealthy groups - red meat, butter and stick margarine, cheese, pastries and sweets, and fried or fast food.

To adhere to and benefit from the MIND diet, a person would need to eat at least three servings of whole grains, a green leafy vegetable and one other vegetable every day — along with a glass of wine — snack most days on nuts, have beans every other day or so, eat poultry and berries at least twice a week and fish at least once a week. In addition, the study found that to have a real shot at avoiding the devastating effects of cognitive decline, he or she must limit intake of the designated unhealthy foods, especially butter (less than 1 tablespoon a day), sweets and pastries, whole fat cheese, and fried or fast food (less than a serving a week for any of the three).

Berries are the only fruit specifically to be included in the MIND diet. "Blueberries are one of the more potent foods in terms of protecting the brain," Morris says, and strawberries also have performed well in past studies of the effect of food on cognitive function.

“The MIND diet modifies the Mediterranean and DASH diets to highlight the foods and nutrients shown through the scientific literature to be associated with dementia prevention.” Morris explains. "There is still a great deal of study we need to do in this area, and I expect that we’ll make further modifications as the science on diet and the brain advances.”


Scientists discover experimental therapy for chronic inflammatory bowel disease

UCLA scientists have discovered an experimental therapy capable of suppressing the development of ulcerative colitis, a disease that causes inflammation in the digestive tract. Ulcerative colitis patients have an increased risk of developing colon cancer, but doctors still are unsure why.

The treatment uses a chemical to block an RNA molecule that’s involved in the transmission of genetic information and is typically found in high levels in people with ulcerative colitis.

Dr. Dimitrios Iliopoulos, a member of UCLA’s Jonsson Comprehensive Cancer Centre, and Dr. Christos Polytarchou, a UCLA assistant professor of digestive diseases, examined 401 samples of colon tissue from people with UC, Crohn’s disease, irritable bowel syndrome, sporadic colorectal cancer and colitis-associated colon cancer, and compared them to healthy specimens.

The authors expedited the process of identifying the most effective treatment using sophisticated computer programmes and robotics (video) that combined molecular and clinical data, and enabled them to zero in on key genetic information. The state-of-the-art approach shortened the drug discovery process, which might have taken five or six years, to just two.

“We evaluated this drug in mice with ulcerative colitis and colon tumours and found that in both cases it was highly effective to suppress these diseases,” Iliopoulos said.

http://tinyurl.com/q218x8

More Balls Than Most now has “wheels”

More Balls Than Most, PinkDrive’s brother campaign, finally got their own vehicle. MBTM can now travel and educate men, more frequently and actively, on prostate and testicular cancer.

“We promised our corporate and our sponsors, and we promised South Africa that we would get our first educational vehicle on the road for prostate and testicular cancer. Well that day has arrived, and we are excited by the new possibilities that arise with this vehicle” said Noeline Kotschan, CEO and Founder of MBTM and Pink Drive.
unique procedure enabled me to have a skin and nipple sparing mastectomy free from animation deformity, which happens when implants are placed beneath the pectoral muscle - mine were placed over the muscle,” said Hopkins. “Being his patient and working side-by-side with Dr. Becker has changed my life and will hopefully change the lives of many others.”

The majority of breast reconstructions performed today are done as a two-staged procedure where an expander is placed in the sub-muscular position followed by exchange for an implant several months later after the tissue has expanded. Sometimes, in the appropriate patients, a single-stage reconstruction can be performed where an implant is placed in the sub-muscular position at the time of the mastectomy.

The new, above the muscle, single-stage procedure developed and studied by Becker preserves the nipple, areola and surrounding skin. Becker uses a vertical mastectomy incision, a dermal flap for coverage, and a definitive adjustable smooth saline implant.

“Procedures that spare the nipple and skin have been shown to be oncologically safe and allow for much more flexibility in implant-based breast reconstruction,” said Becker. “Single-stage breast reconstruction will become more important as there continues to be increasing financial strains on our healthcare system.”


A simple tableware switch could reduce exposure to a potentially harmful substance

In households with kids - or grown-up klutzes - a durable set of melamine plates and bowls is a must. But studies suggest that heat and acid can cause melamine from dinnerware to seep into food and potentially cause harmful health effects. Now scientists show that substituting stainless steel containers for melamine ones when serving hot food could reduce the amount of the substance in people’s bodies. Their report appears in ACS’ journal Environmental Science & Technology.

Although officials largely stamped out the practice of adding melamine to food, most people continue to be exposed to the substance, an industrial chemical also used in other plastics, flooring and whiteboards. Some research has suggested that even small amounts could increase the risk of urinary stones or kidney problems, and one major source of the material is tableware.


Real-time imaging of lung lesions during surgery helps localise tumours and improve precision

More than 80,000 people undergo resection of a pulmonary tumour each year, and currently the only method to determine if the tumour is malignant is histologic analysis. A new study reports that a targeted molecular contrast agent can be used successfully to cause lung adenocarcinomas to fluoresce during pulmonary surgery. This enables real-time optical imaging during surgery and the identification of cancer cells. The results are reported in The Journal of Thoracic and Cardiovascular Surgery, the official publication of the American Association for Thoracic Surgery (AATS).

“This approach may allow surgeons to perform resections with confidence that the entire tumour burden has been eliminated. In the future, with improved devices and molecular contrast agents, this approach may reduce the local recurrence rate and improve intra-operative identification of metastatic cancer cells,” explained lead investigator Sunil Singhal, MD, of the Department of Surgery, University of Pennsylvania Perelman School of Medicine.

In this proof-of-concept study, 50 patients (ages 25-85 years) with diagnosed adenocarcinoma received 0.1 mg/kg of a fluorescent folate receptor alpha (FRα)-targeted molecular contrast agent four hours before surgery.

In seven of the 50 cases (14%), the tumour could easily be identified by its fluorescence. The tumours ranged in size from 1.1 to 8.0 cm, but size did not influence fluorescence. All of these tumours were within 1.2 cm of the lung surface.

Of the remaining 43 tumours, 39 appeared fluorescent after the underlying tissue was opened and the tumour exposed. The fluorescence was uniform across the tumour’s surface, and the demarcation between tumour and normal surrounding tissue was clearly visible. On average, the optical imaging was quick, ranging from five to 15 minutes.


Cancer prehabilitation

Cancer patients who do rehabilitation before they begin treatment may recover more quickly from surgery, chemotherapy or radiation, some cancer specialists say. But insurance coverage for cancer “prehabilitation,” as it’s called, can be spotty, especially if the aim is to prevent problems rather than treat existing ones.

It seems intuitive that people’s health during and after invasive surgery or a toxic course of chemo or radiation can be improved by being as physically and psychologically fit as possible going into it. But research to examine the impact of prehab is in the beginning stages.

Prehabilitation is commonly associated with orthopedic operations such as knee and hip replacements or cardiac procedures. Now there’s growing interest in using prehab in cancer care as well to prepare for treatment and minimise some of the long-term physical impairments that often result from treatment, such as heart and balance problems.

“It’s really the philosophy of rehab, rebranded,” says Dr. Samman Shahpar, a physiatrist at the Rehabilitation Institute of Chicago.

The main component of cancer prehab is often a structured exercise programme to improve patients’ endurance, strength or cardiorespiratory health. The clinician establishes baseline measurements, such as determining how far a patient can walk on a treadmill in six minutes, and may set a goal for improvement. He also evaluates and addresses existing physical impairments, such as limited shoulder mobility that could be problematic for a breast cancer patient who will need to hold her shoulder in a particular position for radiation. Depending on the programme, patients may also receive psychological and nutritional counseling or other services.

http://tinyurl.com/qfg7dr9

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