VISION
COPING WITH CANCER
CANCER BUDDIES www.cancerbuddies.org.za
VISION, APRIL 2015

WHO says that withholding results from clinical trials is unethical

"Failure to publicly disclose trial results engenders misinformation, leading to skewed priorities for both R&D and public health interventions," said Marie-Paule Kieny, an assistant-director at WHO, in a press statement recently. "It creates indirect costs for public and private entities, including patients themselves, who pay for sub-optimal or harmful treatments."

For the first time ever, the World Health Organisation (WHO) has taken a position on clinical trial results reporting, and it's a very strong position! The WHO now says that researchers have a clear ethical duty to publicly report the results of all clinical trials. Significantly, the WHO has stressed the need to make results from previously hidden trials available. Ben Goldacre said, "This is a very positive, clear statement from WHO, and it is very welcome." Ilaria Passarani from the European Consumer Organisation BEUC called it "a landmark move for consumers."

The WHO has called on organisations and governments to now ensure that all trials get reported and Ben Goldacre has set out some practical suggestions on how to make this happen.

Clinical trials go unpublished for a variety of reasons. Sometimes a study's sponsor prefers not to call attention to unwelcome results; sometimes researchers have trouble getting a journal to print their findings - for instance if they show a treatment had no effect; and sometimes scientists never get around to writing a manuscript. But withholding results leads to "publication bias," which causes treatments to seem more or less effective than they really are, and it can put volunteers in future trials at risk unnecessarily.

Ben Goldacre, a co-founder of the advocacy group AllTrials, praises WHO's "landmark position statement", but says it's not enough. To make sure that researchers follow WHO's advice and fulfill their reporting obligations, Goldacre recommends independently conducted audits. For every trial entered in a trial registry more than 12 months ago, auditors can simply check whether the results have been published and post their findings. That "would allow us to name and shame poor performers, and also to reward best practice," Goldacre writes.

Manny de Freitas Foundation host colon cancer awareness event

The MdFF (Manny de Freitas Foundation) held its monthly cancer awareness breakfast and colon cancer was the focu. The Bem Bom coffee shop in Bedfordview was packed to capacity on 28 March.

Executive Director of the MdFF, Jeanette de Freitas said that it was decided to focus on colon cancer as it is one of the lesser known cancers. Colon cancer develops in the colon or rectum when the abnormal growth of cells occur.

Founder of the Manny de Freitas Foundation, Manny de Freitas was present. In his address he explained the aim of the Foundation; to raise funds so that alternative treatments and cures for cancer can be properly researched.

Also present was head of the newly-formed Men's group of the MdFF, Richard Warren-Tangney. The first men's group function will take place in May.

Wings of Hope spreading awareness

Gail Myburgh and Christel Klima, directors of the Wings of Hope, delivered a presentation on regular mammography and breast self examination to a gathering of domestic employees in Bryanston recently. The response was highly rewarding and there have been calls for more of these community services.

Join us for a walk around the lovely suburb of Lonehill in aid of Cancer Buddies, CanSurvive Support Groups and their CanAssist Feeding Scheme

CanSurvive CANCER SUPPORT GROUPS

More details and entry forms available shortly

CANCER BUDDIES www.cancerbuddies.org.za

Synthetic drugs: evidence that they can cause cancer

Almost weekly, a new synthetic psychoactive drug comes onto the market somewhere in Europe that can be ordered legally and easily, for example as an incense blend, via the Internet. Synthetic cannabinoids are difficult to identify chemically and the possible unwanted toxic effects that can occur following their consumption have so far barely been investigated. As part of the international EU project "SPICE II Plus", which is now coming to an end, scientists from the MedUni Vienna's Institute for Cancer Research have now also found evidence that synthetic substances damage the DNA of human cells and can therefore possibly have cancer-causing effects.

Synthetic cannabinoids, similar to tetrahydrocannabinol (the psychoactive ingredient of marijuana), bind to cannabinoid receptors in the human brain, triggering similar neurophysiological effects. These synthetic cannabinoids are marketed in incense mixtures as "legal highs" via the Internet and are "flooding the market", as Siegfried Knasmüller from the Institute for Cancer Research at the MedUni Vienna warns.

"The substances are directly active, in other words they are not activated via enzymes that metabolise foreign substances", explains Knasmüller. "The respiratory organs and the digestive tract especially are subjected to increased concentrations of these drugs. Our investigations on human cell lines in the laboratory have shown that synthetic cannabinoids, in the high concentrations found in cells in the oral cavity or in the lungs, for example, are likely to trigger damage to the DNA that may have significant consequences for the consumers of such substances. They damage chromosomes, and this is directly associated with cancer."

Synthetic cannabinoids bind very differently and some have an effect even in very small quantities. Between 2005 and 2012, the European Union's early warning system registered just under 240 new psychoactive substances that were disguised as incense blends, bath salts or plant fertiliser, and around 140 of them contained synthetic cannabinoids.

http://tinyurl.com/o4ne48y

HELP CANSURVIVE TO PROVIDE SUPPORT FOR CANCER PATIENTS

Why is the doctor ANGRY?

I had a patient this week that really screwed up his medical care when he experienced a predicted side effect of curative chemotherapy. Despite clear instructions and access to every number my partners, my staff and I have, including office, triage, cell, and answering service, he did not reach out. Day-by-day he lay in bed, as he grew weaker and multiple systems failed. No one contacted me. Finally, he sent an email to a doctor 3000 miles away, in California. That doc forwarded the email to me. I sent the patient to the hospital.

Did we rush to the emergency room, to salvage his life? Of course. Were there innumerable tests, complex treatments, multiple consults and an ICU admission? You bet. Did I patiently explain to him what was happening? Yes. Did I look him in the eye and tell him that I was upset, that he had neglected his own care by not reaching out and in doing so he violated the basic tenants of a relationship which said that he was the patient and I was the doctor? Did I remind him what I expect from him and what he can expect from me? You better believe it, I was really pissed!

The practice of medicine for most doctors is fueled by a passion to help our fellow man. This is not a vague, misty, group hug sort of passion. This is a tear-down-the-walls and go-to-war passion. We do not do this for money, fame, power or babes; we do this because we care. Without an overwhelming desire to treat, cure and alleviate suffering, it would not be possible to walk into an oncology practice each morning. Therefore, just as we expect a lot of ourselves, we darn well expect a lot out of our patients.

I know that patient autonomy gives each person the right to decide what path they wish to walk. I really understand, after 27 years in practice, that not everyone is going to listen to me and that I occasionally fail or am wrong. I welcome a healthy debate and ongoing interaction about decisions. In the end, the patient is in charge and I am just the guide. That does not mean that I am not going to try to do the best for every patient and that certainly does not mean I do not care.

Often when a patient makes poor and arbitrary changes in medical care, it reflects denial and an attempt to maintain control. These are critical needs and must be respected. However, there is a line which if patient or doctor cross, tragic, unnecessary things occur. The dread disease gives not quarter, even if I am tired, distracted, depressed or ignorant. Cancer demands my complete commitment to its destruction. It demands the same focus on battle from patients.

Therefore, when patients stray without good reason, I get anxious.

Dr. Salwitz is a Clinical Professor at Robert Wood Johnson Medical School.

He lectures frequently in the community on topics related to Hospice and Palliative Care and has received numerous honours and awards, including the Physicians Leadership Award in Palliative Care.

His blog, Sunrise Rounds, can be found at http://sunriserounds.com

When they make bad decisions I get upset. When they needlessly modify treatment, my head begins to spin. When patients yell at my staff, while I understand their stress, I worry they will undermine their care. And because this is oncology and because the stakes are so high, in the most direct and supportive manner, I will let the patient know.

I think one of the differences between young doctors and us old salts, is we how express such anger. Newer docs are full of fresh vim-and-vinegar passion and so upset by the harm that is about to occur, that they raise their voices and may berate their patients. Senior docs know, because they have fallen into the losing-your-temper trap, that this backfires. Patients, already under stress, cannot cope with a shouting off-the-wall physician. Experienced voices instead drop, words slow and we sit down on the bed and touch a hand, rather than pace and punch the wall. Do not mistake controlled continence for calm or uncaring; inside we are seething, fuming, on fire. I tell you, until the day we die, we really get pissed!

Beating difficult disease involves an unwritten contract between patient and doctor. Each has their role, and the patient has much more to lose by violating that agreement. If you do not like the treatment, make a change. Let the doctor know, negotiate a new plan, change caregivers if you need. But, once you set that plan, once the two of you decide on the steps to be taken, it is up to you and your doctor to each do their jobs. Cancer cannot be beaten any other way.

Cancer Chaos

One of the first things I teach medical students is to be aware that they have arrived in a bizarre land. The strange things they see, the disturbed experiences they have, the weird stories they hear, are like noting else in life. I advise students to stay in touch with their feelings, to note what shocks, frightens, or embarrasses them. Remember those emotions now, because as doctors learn their craft they learn to control those reactions. They create order from confusion, and the wild world of medicine seems to make sense. However, for their patients, first entering the healthcare maelstrom, it will always be chaos.

Much of the practice of medicine is about organisation and structure; using data and measurement to apply scientific principles to variant biology. From the simplest concepts of height, weight, and blood pressure to the esoteric study of molecular cancer mutations, we change the "sick old lady," to a 78 year-old female with acute respiratory desaturation (89%), from nonischemic cardiomyopathy (32%), exacerbated by a normochromic normocytic (82) anemia (8.3), from chemotherapy (V58.1), with congestive heart failure (428.0), induced by saline resuscitation (1500cc) treatment of neutropenic (0.8) sepsis (103.4), and shock (88/47); in Room 4, Bed 1, 5N.

Medical care demands we digitise the "old lady." This process makes analysis, decision-making and treatment possible. Each number is in its place, each box checked and tabulated; all is calm and well. The problem is we fool ourselves into believing that we have forged from disorganisation a global order that applies to the whole person and family.

The reality is that while we may sterilise a part of each person's life, that part we call medicine, we can never sooth the chaos. Confusion, variation, originality and endless change are what make human beings special. The scientific model cannot be applied to all

(Continued on page 4)

Cancer Chaos (cont)

experience or to the global reaction to illness. If we expect objectivity and structure, simply because we have organized health events, we fail to appreciate the complexity of our patients and will universally fail to give the best in health care.

Life for patients and their families is so much more than data. It is soaked in abstract ideas, dysfunctional decisions, social influence and emotion. Why did I deserve this? How will the cancer effect and change my relationships, my marriage, my children? What about my job, what will I do to make money or to justify my worth? Who will mow the lawn? Has God deserted me? Am I so altered that I am no more? With the loss of strength, how I will I express or share passion? How beautiful is the sunset! What about suicide? Will my family "catch" the disease? What will tomorrow's, tomorrow, bring?

Life is myriad. Cancer is chaos. To think that the superficial organization of medical care brings universal calm is to believe that putting a top on a boiling pot quiets the seething waters inside; the kettle looks neat, quiet, but the metal grows hot and will, in time, boil over. The "lady," is also a grandmother, church secretary, struggling artist, world traveler, friend, union shop steward, lover and is surrounded by family, neighbors and even enemies.

We gain from recognition that there are major limits in the application of clinical structure. Doctors must accept that what happens to their patients is much more than can by typed into a history, physical, diagnosis and treatment plan. Physicians must be sensitive and vigilant to the labyrinth that is their patient's lives and how it affects them and therapy. It is not just writing a prescription.

Perhaps more important, every family and patient need to learn that, as in the rest of life, chaos is normal. Every patient and family enters the medical arena with all the variation, strength and weakness, which has been their whole life. Disease inflames that history and adds new layers of change. No journey is a straight line. Each person is different and each day a new unstable experience.

Life is not neat, digitized, or organized. Life is strange and messy. That is what makes life hard, but it is also what makes it wonderful. Disease, cancer, is part of that chaos, increasing the intensity. That is normal, healthy and to be expected. It is a tough journey, but we can make it. Moreover, just maybe, that is what makes life worth l iving.

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: starting at 09:00 at

MIDRAND - 25 April -
in the Boardroom (follow the signs) at
Netcare Waterfall City Hospital

HEAD and NECK Group - 7 May
at Rehab Matters, Rivonia

PARKTOWN - 9 May, Hazeldene Hall
(opp. Netcare Park Lane Hospital)

Enquiries:

Bernice 083 444 5182 or bernicelass@gmail.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.

You're in safe hands

Celebrate with a ginger "mocktail"

Limiting alcohol is a good way to promote better health and lower cancer risk. Researchers have linked regular alcohol consumption to head, neck and liver cancers, and believe it may be a culprit in higher risk for colon, rectal and breast cancers. Instead of overdoing it on the bubbly, try this delicious fizzy mocktail, featuring fresh ginger, anise and cinnamon from the American Institute for Cancer Research:.

1/3 cup (3 oz.) thinly sliced, fresh ginger
1 whole star anise
3-in. piece stick cinnamon
1½ cups cold water
Agave, maple syrup, or honey
1 lemon, cut lengthwise into 4 wedges

To serve hot: 3 cups hot water

To serve cold: 3 cups cold seltzer or club soda

Place ginger, star anise, cinnamon and water in small saucepan. Bring water to a boil over medium-high heat, reduce heat and simmer for 5 minutes. Cover, and set aside to steep for 30 minutes. Strain hot ginger concentrate into heatproof measuring cup.

To serve hot, divide hot concentrate among 4 mugs. Add 3/4 cup hot water to each, and sweeten to taste. Add lemon wedge to squeeze into hot gingerade.

To serve cold, cool ginger concentrate to room temperature. Divide among 4 tall glasses. Add 6 ice cubes to each glass, then pour in 3/4 cup club soda. Sweeten cold gingerade to taste, add lemon wedge to each glass, and serve.

Unused concentrate will keep, tightly covered in refrigerator, for 3 days. Makes 4 servings

CONTRIBUTIONS FOR PUBLICATION IN "*VISION*" NEWSLETTER

Comments, articles, letters and events submitted for publication in VISION are welcomed and can be sent to: cansurvive@icon.co.za.

Let us know what items you would like to see more of in VISION.

"Unsilenced" the video now with Chinese sub titles!

This project was born from the PhotoVoice project. A student from the US, Jenna Frerichs, contacted me and said she and her brother, Travis, wanted to make a video in SA. She had funding from her university to do this project.

Preliminary results had showed the impact that stigma had and it was thought that, in line with the LiveStrong stigma project, we would like to add a dimension to educate people about the impact stigma has. Jenna and Travis came to stay with me in 2013, shot the footage and then edited it! Voices and stories from our Photovoice project were used to highlight the impact of stigma.

Dr Jimmy Holland from Memorial Sloan Kettering was so impressed with the video that she want it to be used by Aortic to drive change in Africa and, more recently, PLWC was asked by Kristen Ho if we would be prepared to do Chinese sub titles as they were also struggling with stigma issues and want to use it in China! Quite special I think.

You can watch the video at https://www.youtube.com/watch?v=-7vLgUzAj2Q.

- Linda Greeff

How it came about ...

I came to know Dr. Lynn Edwards when she paid a visit to where I work at the Taiwan Breast Cancer Alliance. TBCA is the platform for breast cancer patient support groups in Taiwan, providing medical lectures, cancer prevention programs, workshops, consulting services, volunteer training, etc. to all patients and survivors in Taiwan.

I was very moved when Dr. Lynn talked about the current breast cancer status in South Africa, the diversity of peoples and languages, and the project"Photovoice" she has been working on. When Dr. Lynn sent me the link of the film "Unsilenced", I was touched by the courage displayed by the men and women coming out to fight against cancer. I asked Dr. Lynn if she could put up a Chinese subtitle, so when I link the film to TBCA fan page on Facebook and blog, more people can understand it. I told her that I was willing to do the translation if I could have the transcript. Even though Dr. Lynn was very busy, she managed to give me the transcript in less than two weeks. Not long after I sent in my translation, I received the link to the film with Chinese subtitle. I have to admit that I became very emotional when I saw the film again.

I want to thank all the men and women who contributed to make this amazing film. The work to fight against cancer is hard and full of obstacles. Please keep up the work, and my heart will always be with you.

- Kristen Ho

Tygerberg Hospital prepares for increase in cancer patients

With the World Health Organisation predicting steady growth in the number of cancer patients worldwide, the radiation oncology division at Cape Town's Tygerberg Hospital has been equipped with world-class equipment to enable it to treat patients faster and more effectively.

"We're privileged to have very progressive and forward-thinking CEO and provincial authorities who see the value of investing in state of the art equipment, which enables us to deliver the same quality of care found in hospitals in Europe and the US," says professor Hannah Simonds, head of radiation oncology at Tygerberg and associate professor at Stellenbosch University.

"The Tygerberg radiation oncology division currently treats around 2500 patients a year, with an increase of around 300 year on year. As patient cancer awareness improves and life expectancy increases due to improved management of other conditions, we expect to see oncology patient numbers increasing. So we have to be prepared," says Simonds.

South African oncology is characterised by a larger number of patients in the advanced stages of cancer, as well as a large number of patients suffering from other conditions, such as HIV and TB. The division of radiation oncology at the Stellenbosch University and the Tygerberg Hospital is a national and international leader in cancer treatment with radiation therapy and chemotherapy, and is internationally recognised for its excellence in clinical treatments, education and research. Treatments include Intensity Modulated Radiation Therapy (IMRT), Four Dimensional Computed Tomography (4D CT) and Four Dimensional Positron Emmision Tomography-Computerised Tomography (4D PET-CT), Linear Accelerators for external beam radiotherapy and radioisotopes in brachytherapy as well neutrons and protons in collaboration with I-Themba labs to treat those cancers that cannot successfully be treated with photons and electrons. The unit is equipped with four Digital Linear Accelerators and the MOSAIQ oncology information system that limit the radiation exposure of normal tissue and side effects.

Are you a cancer patient or survivor? I need your help please!

Torsten Koehler (Testicular cancer survivor & Founder of the "Love your Nuts" project)

We need cover photos for the cancer school programme to be launched in South African schools. The programme is about cancer in general (not only testicular). See my website for more details: http://www.love-your-nuts.com/projects.html

The photos can be of young, old, male, female people and obviously the whole range of skin colours - because cancer is not picky! It could be you ... bald, a wig, a bandana, ... or the healthy you. Whatever you're comfy with!

Please mail me your photo in high resolution. (By mailing me the photo you are giving permission that I may use your photo free of charge for the cancer school programme and advertising/awareness related to that.)

Please share this with other cancer survivors/patients that you know. Maybe they would like to support this cause too.

Thanks for your support!

Running in Cap & Undies on World Cancer Day

With my project "Love your nuts – Testicular cancer in a nutshell" I like to raise awareness among young men because testicular cancer is most common between 15 and 38.

At the Lace-up for Cancer fun run (organised by HPCA (Hospice Palliative Care Association of South Africa – www.hpca.co.za) in Mouille Point on World Cancer Day (4 February) I challenged guys to run in "Love your nuts" underwear and caps only. 36 people were ballsy enough to join. Four of them were women who like my idea to get men involved in their health issues.

Top: GermanSchool: 9 teachers and students from the German International School Cape Town joined the run.

Below: LYN supporters & LYN starters: 36 people were ballsy enough to join the fun run in underwear to raise awareness for testicular cancer. Four of them were women who like my idea to get men involved in their health issues.

LOVE YOUR NUTS
Testicular Cancer Education in a Nutshell

Love your Nuts on sexual health talk show

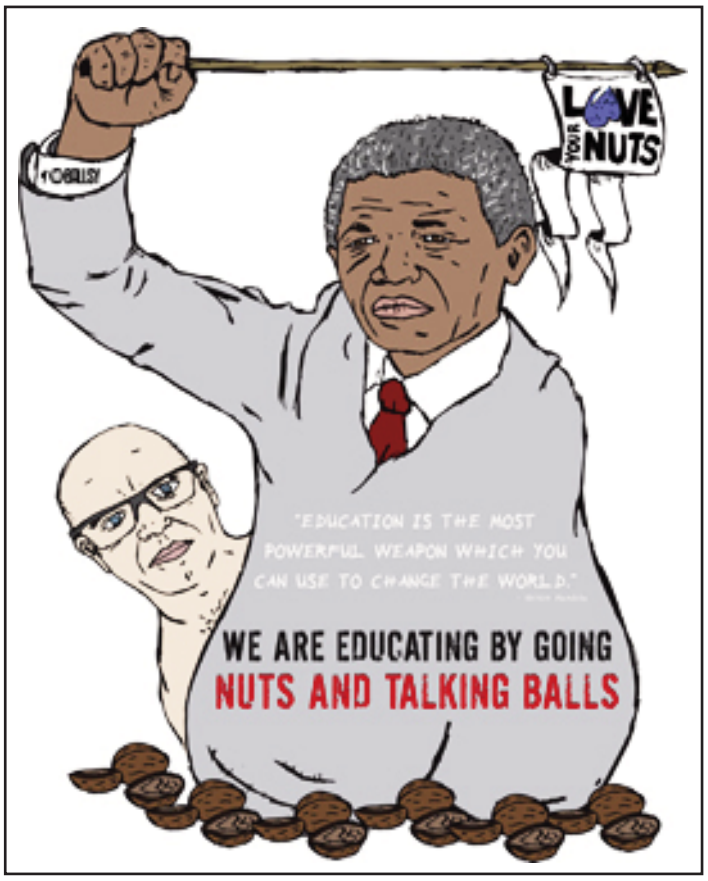
On Wednesday 8 April 2015 at 20:30 the show was aired on Channel 190 DStv (ED Channel). It was a discussion on facts about testicular cancer by Prof. Michael Herbst (Head of Health – CANSA) and me talking about my cancer journey and the impact on my life as well as my project "Love your nuts – Testicular Cancer Education in a Nutshell" (www.love-your-nuts.com)

South Africa only African country participating in global exhibition!

In a world focused on celebrities and pop culture, Mr. Ballsy was inspired to combine these topics with art to draw attention to his (and mine) mission in life - testicular cancer awareness!

The Celebrity Balls Exposed art display is a global initiative to increase awareness with simultaneous art exhibits in ten countries during April, Testicular Cancer Month.

Each individual Ballsy piece is unique to the country it resides in, displaying native celebrities embellishing with two extra, very distinctive characteristics. Each Ballsy piece was hand-drawn by Mr. Ballsy (Thomas Cantley) – www.mrballsy.com and then brought digitally to life by Nicole Richard.



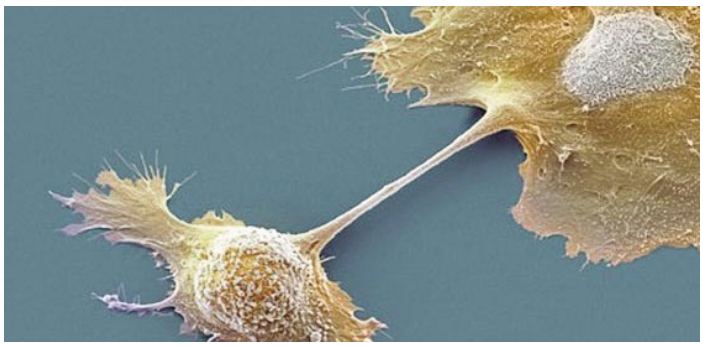
Pancreatic cancer breakthrough: scientists turn cancer cells into normal cells

by introducing a protein called E47. E47 binds to specific DNA sequences and controls genes involved in growth and differentiation. The research provides hope for a new treatment approach for the more than 40,000 people who die from the disease each year in the United States.

"For the first time, we have shown that overexpression of a single gene can reduce the tumour-promoting potential of pancreatic adenocarcinoma cells and reprogram them toward their original cell type. Thus, pancreatic cancer cells retain a genetic memory which we hope to exploit," said Pamela Itkin-Ansari, Ph.D., adjunct professor in the Development, Aging, and Regeneration Program at Sanford-Burnham and lead author of the study published today in the journal Pancreas.

The study, a collaborative effort between Sanford-Burnham, UC San Diego, where Itkin-Ansari holds a joint appointment, and Purdue University, generated human pancreatic ductal adenocarcinoma cell lines to make higher-than-normal levels of E47. The increased amount of E47 caused cells to stall in the G0/G1 growth phase, and differentiate back toward an acinar cell phenotype.

In-vivo studies showed that when the reprogrammed cancer cells



Scanning electron micrograph of pancreatic cells

were introduced into mice, their ability to form tumours was greatly diminished compared to untreated adenocarcinoma cells.

"Presently, pancreatic adenocarcinoma is treated with cytotoxic agents, yet the average survival for patients post-diagnosis is merely six months, and the improvements in therapies are measured in days," said Andrew M. Lowy, M.D., professor of surgery at the UC San Diego Moores Cancer Centre and co-chair of the National Cancer Institute's Pancreatic Cancer Task Force. "The finding that we can differentiate these cancer cells back to a non-threatening phenotype is encouraging. Indeed, there is a precedent for cell differentiation therapy in that the approach has been used to treat acute promyelocytic leukemia (APL) and some neuroblastomas successfully."

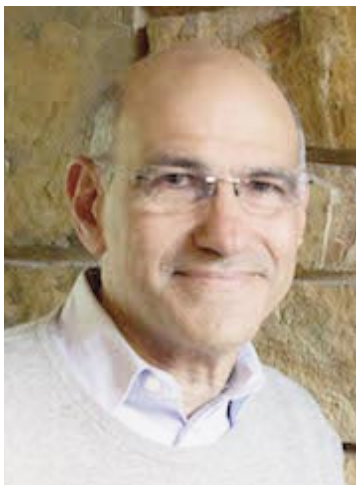
http://beaker.sanfordburnham.org/2015/04/pancreatic-cancer-breakthrough-scientists-turn-cancer-cells-into-normal-cells/

How new medicines are cheating death

It hit me again the other day as I hosted a lung cancer event in Tampa, Florida. If we get sick, aren't we lucky if medical science - just then - has something new, either approved or in a promising clinical trial, that can help us get well?

Floridian Pam Griffith was dying from advanced lung cancer. Standard drugs weren't working, and the tumours were obvious in several places in her body. With some effort, she was fortunate to enter a clinical trial for a new kind of medicine, a "checkpoint inhibitor" that allows her immune system to not be outfoxed by cancer cells.

It has worked. Pam has gone from almost being on her deathbed to playing golf three times a week and may step that up now to four. She feels very good, and - having just met her in person - she looks great. Another man I met, Tony Benchina, was also dying. Soon after retiring after 41 years as a family physician, he got the kind of bad news he had given many others. Again, standard medicines weren't working, and the new medicine that worked for Pam caused problematic side effects for Tony. But, thank God, there was yet something else that was new. It's not approved yet, so Tony is in a clinical trial. But it is working. He is gardening and cooking once again. Remember, we are talking about the cancer that takes more lives than any other - lung cancer. This is so hopeful!



Andrew Schorr is the author of the new book The Web-Savvy Patient: An Insider's Guide to Navigating the Internet When Facing Medical Crisis. He is a respected medical journalist and 15-year leukemia survivor. He founded healthtalk.com and patientpower.info and has hosted almost 3,000 online talk shows for patients with chronic conditions and cancers. Many of America's leading medical centers support his work.

http://tinyurl.com/o6vmu6n

I am meeting people who have the good fortune to be sick at a time when there are truly breakthroughs to give them back better health. When you meet scores of people like this, you feel grateful to the often unseen researchers who made this happen.

Of course, there are obstacles, you or family members may be afraid of you becoming a "guinea pig" in a clinical trial, or the requirements and travel for checkups may be too tough. You may have insurance issues, or your local doctor, who you like, may not be in the know. After all, how can a general doctor keep up on everything that is new or promising? We discuss all of these issues on Patient Power all the time, so please join our community, so you are "in the know."

There is not a new medicine for everything. Sadly, many people with advanced cancers do not have a breakthrough to count on. But there is a change. Wouldn't it be great if the change was happening in the condition that afflicts you right now? If that is happening, be sure you can take advantage of it!

Connect with an active community of medical experts and learn about a wide range of topics. You can join the Patient Power community at https://www.patientpower.info/user/register

Dates to diarise

25 CanSurvive Cancer Support Group, Netcare Waterfall City Hospital, Midrand, 09:00

28 Cancer Buddies, Rondebosch. Cancer Advocacy the role of Cancer Survivors by Salome Meyer

30 Reach for Recovery, Cape Peninsula 10:00. Pilates: History and exercises for breast cancer patients

May 2015

7 CanSurvive Head and Neck Support Group, at Rehab Matters, 1 De la Rey Rd. Rivonia at 18h00

9 CanSurvive Cancer Support Group, Hazeldene Hall, Parktown 9:00

9 Wings of Hope, German International School, Parktown, 09:30 for 10:00

12 CHOC Annual Golf Day, Killarney Country Club.

12 Reach for Recovery, Roodepoort Centre for the Aged, Robinson Street, Horizon14h00

13 Reach For Recovery, Johannesburg, 19 St John Road, Houghton 13:30

16 Bosom Buddies, Hazeldene Hall, Parktown, 09:30 for 10h00

19 Prostate & Male Cancer Support Group, Auditorium, Constantiaberg MediClinic, 18:00

23 CanSurvive Cancer Support Group, Netcare Waterfall City Hospital, Midrand, 09:00

28 Reach for Recovery, Cape Peninsula 10:00 Recurrence of Breast Cancer.

June 2015

4 CanSurvive Head and Neck Support Group, at Rehab Matters, 1 De la Rey Rd. Rivonia at 18h00

7 International Cancer Survivors Day

7 CanSurvive's Lonehill Relay Walk 8:00

13 CanSurvive Cancer Support Group, Hazeldene Hall, Parktown 9:00

27 CanSurvive Cancer Support Group, Netcare Waterfall City Hospital, Midrand, 09:00

27 Bosom Buddies, Hazeldene Hall, Parktown, 09:30 for 10h00

July 2015

2 CanSurvive Head and Neck Support Group, at Rehab Matters, 1 De la Rey Rd. Rivonia at 18h00

11 CanSurvive Cancer Support Group, Hazeldene Hall, Parktown 9:00

14 Reach for Recovery, Roodepoort Centre for the Aged, Robinson Street, Horizon14h00

15 Reach For Recovery, Johannesburg, 19 St John Road, Houghton 13:30

18 Wings of Hope, German International School, Parktown, 09:30 for 10:00 - birthday.

21 Prostate & Male Cancer Support Group, Auditorium,

CONTACT DETAILS

Cancer Buddies Johannesburg branch, and CanSurvive Cancer Support Groups - Parktown and Waterfall : 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: Nicolene Andrews 0218512255

Cancer.vive, Frieda Henning 082 335 49912, info@cancervive.co.za

Can-Sir, 021 761 6070, Ismail-Ian Fife, ismailianf@can-sir.org.za Support Group: 076 775 6099.

More Balls than Most: febe@pinkdrive.co.za, www.pinkdrive.co.za, 011 998 8022

Prostate & Male Cancer Support Action Group, MediClinic Constantiaberg. Contact Alan Mitchell on 073 560 3067 or alan.mitchell@telkomsa.net, or Can-Sir: 079 315 8627

Wings of Hope Breast Cancer Support Group 011 432 8891, info@wingsofhope.co.za

PinkDrive: febe@pinkdrive.co.za, www.pinkdrive.co.za, 011 998 8022

Bosom Buddies: 011 482 9492 or 0860 283 343, Netcare Rehab Hospital, Milpark. www.bosombuddies.org.za.

CHOC: Childhood Cancer Foundation SA; Head Office: 086 111 3500; headoffice@choc.org.za; www.choc.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, 011 487 2895.

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@gmailcom

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

The probiotic cancer relationship

The average consumer likely has minimal understanding of the use of probiotics. However, these organisms have demonstrated their potential in minimising cancer treatment side effects and reducing cancer risk.

Probiotics are live microbial supplements that beneficially affect the host animal by improving its intestinal microbial balance. They are found in foods such as yogurt, cheese, miso, sauerkraut, pickles, artichokes, oats, and honey. They can also be purchased in supplement form. When ingested, they alter the chemistry of the gut by lowering the pH and altering the microflora.

Probiotics have a promising future in the prevention of several cancers. The most promising evidence is with regards to colon cancer. Probiotic intervention has been shown in studies to bind and deactivate carcinogens. They promote immune function, inhibit carcinogen-producing enzymes, and influence the overgrowth of flora in the gut. A probiotic immune boosting influence provides protection against harmful viral and bacterial strains and promotes tumour inhibition.

Radiation induced enteritis and colitis is a severe complication for cancer patients as it can lead to diarrhoea which can severely affect the hydration and nutritional status of a patient. Some studies have shown that using a Lactobacillus probiotic concoction can reduce the incidence and severity of diarrhoea in these patients. Another type of cancer which may be affected by probiotics is liver cancer. Hepatitis B infection is the main risk factor followed by exposure to aflatoxins, which are toxic compounds produced by fungi.

Probiotics may also play a role in other cancers such as breast cancer and superficial bladder cancer prevention.

http://www.pvhmc.org/Cancer-Care-Centre/Education-Support/Articles-Our-Patients-Details.asp?RID=49

Head and neck cancer on rise in young men

While still considered rare, head and neck cancers are striking younger men at a higher and more rapid rate. And many of the patients do not have the typical cancer risk factors: smoking, chewing tobacco, or consuming alcohol. The human papillomavirus (HPV) 16 infection is now thought to cause more than half of all cases of oropharyngeal cancer, a type of head and neck cancer.

"The head and neck cancers we have found in younger men with no known risk factors such as smoking are very frequently associated with the same HPV virus that causes cervical cancer in women." said Kerstin Stenson, MD, a head and neck cancer surgeon at Rush and a professor of otolaryngology at Rush University.

"Men are more susceptible to these cancers because they don't seem to have the same immune response as women and do not shed the virus like women do," Stenson said.

"For all individuals, the key is in early detection, as with any cancer," Stenson said. He stresses that in addition to being vaccinated, regular visits to the dentist are of importance. "Dentists play a key role in detecting oral cancer. You might not see a primary care physician even once a year, but most people see their dentist twice a year. Having regular dental visits can help catch cancers early to help ensure the best outcome."

http://tinyurl.com/mfcsbk2

Brain tumour cells decimated by mitochondrial "smart bomb"

An experimental drug that attacks brain tumour tissue by crippling the cells' energy source called the mitochondria has passed early tests in animal models and human tissue cultures, say Houston Methodist scientists.

Houston Methodist Kenneth R. Peak Brain & Pituitary Tumour Centre Director David S. Baskin, M.D., and Peak Centre Head of Research Martyn Sharpe, Ph.D. designed a drug called MP-MUS that destroyed 90 to 95 percent of malignant glioma cells, yet in other experiments did not seem to adversely affect healthy human brain cells (in vitro). This complements a soon to be published extensive study showing the same drug can treat human brain cancer grown in the brains of mice. Researchers hope to begin testing the drug in human clinical trials in 2016 or 2017

"We are very optimistic that we'll get there," said Baskin, also Vice Chair of the Department of Neurosurgery at Houston Methodist Hospital. "Our past work has shown that MP-MUS has very low toxicity until it gets into tumour cells. Once it arrives, it is changed to its active form, doing a lot of damage where we want it to, leaving healthy brain cells alone - a bit like a 'smart bomb.' To our knowledge, this is the first known example of selective mitochondrial chemotherapy, which we believe represents a powerful new approach to brain cancer."

Mitochondria are often referred to as the "powerhouses" of cells - including misbehaving cancer cells - because they help cells create energy. In cancer cells this feature is partially switched off, causing cells to rely on other systems that generate energy. The numerous pill-shaped mitochondria in each cell perform a number of other crucial functions, however, and even cancer cells cannot grow and divide without healthy mitochondria.

http://tinyurl.com/k9xm3h7

Is fish oil safe during chemotherapy?

Fish oil supplements might make cancer chemotherapy less effective - but many people with cancer were taking those supplements in a recent survey.

All six of the fish oil supplements the researchers tested contained a specific fatty acid that's been found to reduce the effectiveness of

Tollfree service for cancer patients

PLWC Cancer Buddies now has a tollfree number - it is

0800 033 337

All cancer patients now have access to free cancer support and can ask any questions about cancer and treatment of cancer; the emotional issues related to the cancer journey; questions about side effects of treatment; assistance with accessing resources like wigs, prosthesis, home nursing and hospice. Problems relating to access to treatment or services delivery issues can also be reported .

chemotherapy in mice, the researchers report in JAMA Oncology online April 2.

People receiving chemotherapy should refrain from taking fish oil supplements and discuss any supplement with their doctors, said Dr. Emile Voest, the study's lead author from the Netherlands Cancer Institute in Amsterdam.

"I'm always discussing it with my patients," he said. "Please have an open relationship with me and tell me what you're taking."

He and his colleagues say omega-3 fatty acids are consumed by about a fifth of Americans with cancer - usually through fish oil.

The researchers had previously found that even a small amount of two fatty acids reduced the effectiveness of chemotherapy in mice with cancer. These fatty acids may ultimately enable cancer cells to repair themselves faster after chemotherapy, Voest said.

http://bit.ly/1ClqxXP

A cancer research breakthrough

Queen's University cancer researcher Madhuri Koti has discovered a biomarker that will help lead to better predictions of the success of chemotherapy in ovarian cancer patients. This discovery could lead to better treatment options in the fight against ovarian cancer.

"Recent successes in harnessing the immune system to combat cancer are evidence for the significant roles of a cancer patient's immune responses in fighting cancer," explains Dr. Koti (Biomedical and Molecular Sciences). "Many of these success are based on boosting anti-cancer immunity via different therapies. Such therapies would prove to be most effective when coupled with markers predicting a patient's eventual response to a specific therapy."

Dr. Koti conducted the study in retrospective cohorts of over 200 ovarian cancer patients.

Phase II validations are currently under way in retrospective cohorts of over 500 ovarian cancer patient tumours accrued from the Terry Fox Research Institute-Ovarian Cancer Canada partnered, Canadian Ovarian Experimental Unified Resource.

A major impact of this discovery is that these novel markers, when used at the time of treatment initiation in the specific type of ovarian cancer patient, will help gynecologic oncologists make decisions on additional treatment needed in these patients, thus increasing the potential for patient survival.

Ovarian cancer leads to approximately 152,000 deaths among women worldwide each year, making it a leading cause of gynecological cancer related deaths in women. The study was conducted in collaboration with Anne-Marie Mes-Masson, Centre de Recherche du Centre Hospitalier de l'Université de Montréal, Montreal, and Jeremy Squire, Faculdade de Medicina de Ribeirão University of Sao Paulo, Brazil.

The findings were published recently in the British Journal of Cancer.

http://tinyurl.com/kozysa9

Breast cancer is not one disease, experts say

Breast cancer isn't the same for every woman, even at the cellular level, according to a new statement from four major medical groups focused on the disease.

The report was issued recently by the American Cancer Society, the US Centres for Disease Control and Prevention, the US National Cancer Institute, and the North American Association of Central Cancer Registries. They say that classifying breast cancers according to tumour subtypes could help improve treatment of the disease.

The report "assesses breast cancer as four molecularly defined subtypes, not as a single disease," National Cancer Institute director Dr. Harold Varmus said in an institute news release. "This is a welcome step, [resulting from] medically important information that already guides therapeutic strategies for these subtypes," he said.

The four major molecular subtypes are categorised according to their hormone receptor (HR) status, meaning a chemical receptor lying on breast cancer cells that reacts to hormones such as estrogen. Categorization is also dependent on a tumour cell's activity around the HER2 gene. Both factors can affect how a tumour acts and might be treated, experts say.

The four tumour types are: Luminal A (HR+/HER2-), Luminal B (HR+/HER2+), HER2-enriched (HR-/HER2+), and triple negative (HR-/HER2-).

Experts have long known that the four subtypes respond differently to treatment and have different survival rates, according to the report published March 30 in the Journal of the National Cancer Institute.

Cancer registries across the United States are now recording these breast cancer subtypes, the groups noted, and this new data will help researchers more accurately rank breast cancer by risk. It should also help patients better understand each subtype's impact on their health, the authors said.

Black women had higher rates of the most aggressive breast cancer subtype - triple negative - than other racial/ethnic groups, and also had the highest rates of late-stage disease and they also have the highest rates of breast cancer deaths, the report noted.

http://tinyurl.com/kkumqz6

Stress granules ease the way for cancer metastasis

Tumours that produce more stress granules are more likely to metastasise, according to a study published in The Journal of Cell Biology.

DNA spheres light up to detect cancer

Cancer travels. Large tumours shed cells that move through the body and seed new malignancies. Now scientists are tinkering on the nanoscale to build unusual spheres made of DNA—a molecule that became famous as another shape, the double helix—that can find, tag and potentially kill off these tumour cells.

The spheres look a bit like toothpicks stuck in a small Styrofoam ball. The toothpicks are really a dense crowd of single DNA strands jutting out from a central core. The strands are chosen for their ability to bind to complementary DNA in cancer cells. When a bond happens, it displaces tiny light-emitting molecules stuck to the tips of the DNA in the sphere, essentially sending up a flare that indicates the presence of cancer. The brighter the flare, the more cancer DNA that is present, says Chad A. Mirkin, a chemist and director of the International Institute for Nanotechnology at Northwestern University, who has spearheaded the research.

http://www.scientificamerican.com/editorial/future-of-medicine-2015/?WT.mc_id=SA_TECH_20150324

The results suggest that drugs to inhibit the formation of these structures might rein in cancer metastasis.

When cells are under duress, they curtail almost all protein synthesis and stash their mRNAs in stress granules. These structures help healthy cells, but they also allow tumour cells to survive harsh conditions. A protein named YB-1, which is overexpressed in many types of tumours, accumulates in stress granules, but researchers don't know how YB-1 affects these particles.

University of British Columbia scientist Poul Sorensen and his colleagues found that stressed-out cancer cells need YB-1 to assemble stress granules. Removing YB-1 decreased levels of one stress granule protein, G3BP1. The team discovered that YB-1 attaches to the mRNA encoding G3BP1 and stimulates the protein's production.

To determine the effects of YB-1 in animals, the researchers implanted mice with cancer cells that either made or lacked the protein. A month later, cells in the control tumours carried more stress granules than did the tumour cells missing YB-1. Sorensen and colleagues then implanted mice with tumours that either produced or lacked G3BP1. The control tumours harbored more stress granules than did the G3BP1-deficient tumours, and only the control tumours metastasised.

http://www.medicalnewstoday.com/releases/291323.php?tw

Anticancer drug can spur immune system to fight infection

At low doses, the anticancer drug imatinib can stimulate the bone marrow to produce more neutrophils, which are important for fighting bacterial infections, Emory and Winship Cancer Institute researchers have found.

The findings suggest imatinib, known commercially as Gleevec, or related drugs could help doctors treat a wide variety of infections, including those that are resistant to antibiotics, or in patients who have weakened immune systems. The research was performed in mice and on human bone marrow cells in vitro, but provides information on how to dose imatinib for new clinical applications.

"We think that low doses of imatinib are mimicking 'emergency hematopoiesis,' a normal early response to infection," says senior author Daniel Kalman, PhD, associate professor of pathology and laboratory medicine at Emory University School of Medicine.

Imatinib, is an example of a "targeted therapy" against certain types of cancer. It,blocks tyrosine kinase enzymes, which are dysregulated in cancers such as chronic myelogenous leukemia and gastrointestinal stromal tumours.

Imatinib also inhibits normal forms of these enzymes that are found in healthy cells. Several pathogens – both bacteria and viruses – exploit these enzymes as they transit into, through, or out of human cells. Researchers have previously found that imatinib or related drugs can inhibit infection of cells by pathogens that are very different from each other, including tuberculosis bacteria and Ebola virus.

In the new PLOS Pathogens paper, investigators show that imatinib can push the immune system to combat a variety of bacteria, even those that do not exploit Abl enzymes. The drug does so by stimulating the bone marrow to make more neutrophils and macrophages, immune cells that are important for resisting bacterial infection.

"This was surprising because there are reports that imatinib can be immunosuppressive in some patients," Kalman says. "Our data suggest that at sub-clinical doses, imatinib can stimulate bone marrow stem cells to produce several types of myeloid cells, such as neutrophils and macrophages, and trigger their exodus from the bone marrow. However, higher doses appear to inhibit this process."

The research was supported by the National Institute for Allergy and Infectious Diseases (R01A107246201, R01AI05606701) and the National Heart Lung and Blood Institute (5P01HL08773), and by the Institute Merieux.

http://tinyurl.com/oxsr6vq

One-two punch knocks out drug-resistant lung cancer

Capitalising on a rare opportunity to thoroughly analyze a tumour from a lung cancer patient who had developed resistance to targeted drug treatment, UC San Francisco scientists identified a biological escape hatch that explains the resistance, and developed a strategy in mice for shutting it down.

In experiments that combined the drug the patient had taken with a second compound that blocks off this newly discovered resistance pathway, the researchers were able to durably wipe out cancer cells in mice implanted with cells from the drug-resistant tumour.

"Even in cancers that are responding to targeted therapy by conventional criteria, resistance is already developing," said the senior author of the new study, Trever Bivona, MD, PhD, assistant professor of medicine and member of the UCSF Helen Diller Family Comprehensive Cancer Centre (HDFCCC). "In this work we have begun to crack open the question of why residual disease persists after targeted therapy."

Between 10 and 35 percent of non-small cell lung cancer (NSCLC) patients carry mutations in a gene that codes for a cell-surface protein called the epidermal growth factor receptor, or EGFR. As its name suggests, under normal circumstances, when a growth factor protein locks onto the EGFR, the receptor sends signals that prompt cells to divide and proliferate. But the EGFR mutations seen in NSCLC cause the receptor to be stuck in an "on" position, leading to rampant cell proliferation.

Over the past decade, medications such as erlotinib (trade name Tarceva), which precisely targets the EGFR and tamps down its activity, have advanced the treatment of EFGR-mutant NSCLC beyond chemotherapy, but significant challenges remain. As many as 30 percent of patients exhibit so-called primary resistance to EGFR inhibitors, in which the drugs have no detectable effect. And among patients who do respond, almost all have an incomplete response leading to acquired resistance, in which drug-resistant cells that survive treatment form residual, often lethal, tumours.

http://tinyurl.com/plv6gfs

"Our desire to take medicine is perhaps the greatest feature which distinguishes us from the animals" - Sir William Osler