

VISION

COPING WITH CANCER

VISION, SEPTEMBER 2017

“Bargain price” new leukaemia therapy

The price tag for Novartis’s innovative new leukemia therapy, Kymriah, \$475,000, appears excessive – and their claim that they could have charged much more shows that the drug pricing system in the US is completely broken.

Kymriah will be a one-time, intravenous treatment patients receive after scientists at Novartis engineer a patient’s own immune cells (T-cells) to fight cancer. The drug will treat acute lymphocytic leukaemia, the most common type of childhood cancer in the US. This is the first cancer drug that uses a patient’s own cells to fight cancer.

Wall Street analysts called the nearly half-million-dollar price tag “a bargain” in view of the complex process needed to make the customised drug for each patient. The drug company said in the statement that it was collaborating with Medicare on a plan in which the government would only pay for the treatments if patients responded to them by the end of the first month. However, Vinay Prasad, MD, an oncologist at Oregon Health and Sciences University, emphatically called for a much wider window for refunds - saying that Novartis’s definition of treatment failure will preclude many payers from getting their money back despite patients receiving little if any benefit. He said the company should issue a refund for any relapse within three years.

Just to get Kymriah, patients will have to travel to one of just 32 sites around the US. From there, doctors harvest patients’ white blood cells and ship them off to a Novartis facility in New Jersey where they can be edited and mailed back. The entire process takes about 22 days, the company said. And the \$450,000 price tag covers only Novartis’s role, not the costs of travel, hospitalisation, or any drugs needed to tamp down Kymriah’s side effects. Further, patients could also experience extreme and even life-threatening side effects. One side effect, cytokine release syndrome, can cause high fevers, diarrhoea and vomiting.

STATISTICALLY, MORE THAN HALF OF ALL CANCER PATIENTS DEVELOP SIGNIFICANT PSYCHO-SOCIAL ADJUSTMENT PROBLEMS. THE EMOTIONAL STRESS CAN BE OVERWHELMING, AND NO ONE SHOULD HAVE TO MANAGE IT ALONE.

THE FACTS Fear of death, disruption of life plans, changes in body image and self-esteem, changes in social role and lifestyle, and financial concerns are all realities in the lives of people diagnosed with cancer. In fact at least a quarter suffer MAJOR DEPRESSION which, unless treated, can impact negatively on their QUALITY OF LIFE. (1)

That’s not in question. But a MAJOR ISSUE for psychosocial oncology is how we get to a place where we rapidly, and in a standardised way, identify and appropriately care for patients and families in need of specialised psychosocial and rehabilitation services.

See Advocacy Toolkit #6 on page 9

CANSA Northdale monthly support group

Talking through life after cancer with a group of people going through the same thing is hugely helpful. It doesn’t make the problems go away, but it is a relief to know we aren’t alone in our experiences. Northdale Cancer Support Group meet at the ARV Clinic, Northdale Hospital, Pietermaritzburg on the third Friday of each month at 8:30 am. For more information about the Group, you can contact Phindi Cebisa at 033 897 3139 or email cebisa.phindi@kznhealth.gov.za.



Post-treatment's new normal

by: *Cara Tompot*

While the first few months after a cancer diagnosis typically is the most challenging, there is a different struggle that comes further down the line in cancer survivorship.

Instead of fear and worry, you're left with anxiety and confusion. Rather than making quick yet carefully considered treatment decisions, you're forced to figure out how to keep moving forward and how to get back to the life you had. Of course, life will never be the same.

That's the thing about life-changing diagnoses. They do just that: Change your life. Forever.

My mom was diagnosed with breast cancer at 38 years old. At the time, she had a sporty 12-year-old son and a bouncing baby girl. Naturally, her cancer diagnosis changed a lot of things. In the immediate future, she worried that her children would grow up without their mother and wondered what would happen if she was not able to beat this treacherous disease. There was a distinct shift in her marriage, her friendships and her career.

Fast forward 23 years - more than two decades longer than her initial prognosis - and her life has changed many times since. While she no longer worries her children will grow up without their mother, she does worry her children will face the same diagnosis she did.

And while she no longer wonders what would happen if she didn't beat the cancer, because she has beat the cancer, she still wonders how much longer she has and what toll her years of chemotherapy will ultimately take.

But my mother did not beat cancer to worry and wonder. She beat cancer to keep living, keep creating new memories and conquer more life-changing obstacles.

Managing expectations

After a cancer diagnosis, your life often becomes a never-ending circle of platitudes. Between "make the most of each day" and "live in every moment," we get it. Our survival is a miracle, but the expectation to constantly live life to the fullest just adds even more stress to our already complicated life.

Wait, there's an expectation for cancer survivors?

Yes! We beat the odds. Now, we must continue to make the most of this miracle. So how can we manage these expectations and combat the added pressure? How can we take care of ourselves first? After all, we are the ones who survived. Here, based on life well-spent with my survivor mom:

Eight self-care tips for cancer survivors

You did it! Whether you were diagnosed six months ago or 20 years ago, congratulations! You're a cancer survivor. So what now?

1. Think you first

That's right. Above all else, remember to focus on yourself. I know it sounds selfish, but you deserve it. Think about it: When the doctor told you about the cancer, for a moment, everything felt out of your control. How could this happen to you?

But now it's not like that. You are in control of your choices. Whether it's making a treatment decision or deciding to go back to work, that's up to you.

2. Try Something New.

Hey, you just beat cancer. Why not try something new? Have you always wanted to travel to Europe? Or maybe you want to ride the tallest roller coaster at your local amusement park? It's all up to you. Whether it's something huge like international travel or simply trying to cook a new meal - go for it.

3. Do something you've always loved

Is there something you've loved doing since you were a child or young adult? When was the last time you did that activity? If your answer isn't in the last year, now's the time. Take an afternoon or day or weekend to do some of your favorite activities.

4. Meet new people

Throughout my mom's cancer battle, she has made more friends than a high school "It" girl. Between meeting people at chemotherapy treatments and connecting with other survivors at support groups, her social circle has grown. These new friends can have a major impact on your life because they understand what you are going through. That's exactly what Trina, a 16-year mesothelioma survivor, and Raeleen, a three-year mesothelioma survivor, did. Both women were diagnosed on the same day 13 years apart, and the two bonded over a similar diagnosis.

5. Give back

It's not uncommon to want to give back after winning a cancer battle. Whether you want to fundraise for a nonprofit or become a mentor for someone recently diagnosed with the same cancer, you can make a difference. By giving back to others combating the same cancer, you can help them cope with the same life-altering decisions you did throughout your battle.

6. Get in the zone

Are you interested in yoga? Meditation? Tai Chi? These practices can help you cope with the anxiety you may face as a cancer survivor. By focusing on your mental health and awareness, you can ensure that you are taking the best care of your whole self. Exercise is essential to cancer treatment recovery. Some physicians won't even perform certain operations if a patient is not physically active. Dr. Jacques Fontaine, a renowned thoracic surgeon, asks surgical candidates to walk up a set of stairs before offering surgery as a treatment option. Fitness is key throughout every aspect of a cancer battle - even survivorship.

7. Say "no"

Nobody ever thought it would so difficult to say a short two-letter word. No. No. No. Yet here we are. All of the time, people feel obligated to say yes to various activities and events that you don't want to participate in. Are you feeling overwhelmed or introverted? Say no. It's okay.

8. Think you first ... again

Sound familiar? I can't emphasise the importance of making decisions for yourself. Do what feels right to you. If you aren't a fan of the suggestions and thoughts I've shared here, that's okay. They're meant as advice, not orders. Do what makes you feel whole and right. Don't let someone else's expectations modify your ambitions, motivations and desires. Live your life the way you want to live it. After all, you're the cancer survivor.

This article originally appeared on www.cancerhopenetwork.org and is reproduced with their kind permission. Cancer Hope Network serves cancer patients in the United States and Canada. For more than 30 years, they have been matching cancer patients and their loved ones with cancer survivor volunteers.

Roche cuts price of trastuzumab

Roche is in talks with the South African health department for wider access to trastuzumab, which it sells as Herceptin in the private sector and Herclone in the state sector. Trastuzumab was for the first time included in the government's essential medicines list in June and is recommended for eligible patients in its new breast cancer strategy, which was published on Friday.

The health department is aiming to provide trastuzumab to 500 patients a year at 14 hospitals around the country.

Roche spokeswoman Aadila Fakier said trastuzumab was not yet widely available to state patients but some healthcare facilities were buying the drug and doing so at a lower price than before. Roche sold trastuzumab to the state at about R10,500 a vial, she said, declining to specify the new price. Unlike tender prices, which are published in the Government Gazette, the prices paid by healthcare facilities that buy drugs on "buy-out" are not in the public domain.

The breast cancer strategy says trastuzumab should be provided to patients with HER2 tumours, at three weekly intervals, for a year. But it contains a caveat, saying it must be affordable and not come at the expense of cutting other healthcare services.

http://www.bizcommunity.com/Article/196/398/166675.html#top_story



You are welcome! We would love to meet you!

You are cordially invited to join us at our public meetings where breast cancer patients and their friends and families have an opportunity to mix with other patients and survivors, as well as to listen to talks on issues related to breast cancer.

Next meeting dates: 7 October and 25 November

Time: 9:30 for 10:00am

Venue: Hazeldene Hall, 13 Junction Ave, Parktown, Johannesburg,

FREE ENTRY, Enquiries: louise@mybreast.org.za / 0860 283 343

Stay informed with The Breast Health Foundation:

Facebook: <https://www.facebook.com/BreastHealthFoundation/>

Twitter: <https://twitter.com/BreastBhf>

Instagram: <https://www.instagram.com/breasthealthfoundationsa/>

Website: <http://www.mybreast.org.za/>

Bosom Buddies is a support initiative brought to you by The Breast Health Foundation.



Annual Cancer Challenge Bowls Day

Randburg Bowls Club is proud to present the

Friday 3 November 2017

Start: 12:00 onwards

**Venue: Randburg Bowls Club,
Tinktinkie Road, Randburg**

***24 Teams of 4 players per team
(Each team to include at least one
cancer survivor or cancer fighter)***

NO EXPERIENCE NECESSARY

Entry Fee: R150 per player
(Includes afternoon tea and
"after bowls" snacks)

Prizes, Raffles, Live Music,
Cash Bar and loads of Fun

To book or for more information contact:
Wendy Lobley: 082 469 3874 or email:
wendylobz@gmail.co.za

***Sponsorships: Donations
are welcomed***

All proceeds will go to CanSurvive who support people who are living with cancer. CanSurvive is a registered Non-profit company No. 2016/111301/08

CanSurvive
CANCER SUPPORT

RFR celebrates 50 years of care and support

Reach for Recovery volunteers, all of them breast cancer survivors, gathered in Mossel Bay in July to celebrate 50 years of unique service to patients faced with the trauma of breast cancer diagnosis and treatment.

Chairperson Stephné Jacobs gives the background: "Without the volunteers, our organisation would not exist, so in planning this celebration the priority was to thank and honour them."

For the first time RFR held their own version of the Oscar awards ceremony at which "Voscars" were presented to winning groups in recognition of their achievements in various categories.



Ann Steyn receiving her Presenters Certificate from Stephné Jacobs, Chairperson of the RFR Board of Management.

"We also felt it was vital to motivate, inspire and empower volunteers to ensure our service remains relevant and even more effective going forward. To do this we decided to combine the celebration of our golden anniversary with our first ever conference, aimed at brushing up on knowledge and skills, Stephné explained.

A component of the conference was a brainstorming session where the 160 delegates from all over the country had the chance to air their views and give

ideas on topics such as recruiting new volunteers, and what needs to change or be added to RFR's existing service.

The organisation was founded by Terese Lasser in 1953. After a mastectomy, Terese discovered there was very little information or support available for breast cancer patients. A resident of New York, she



realised that breast cancer survivors who had been through diagnosis and treatment could offer valuable peer support to patients facing the same experience. RFR was launched in South Africa in 1967 after she visited Johannesburg and Cape Town. RFR also offers a breast prosthesis service and breast health education.

In 2013 Stephné realised the importance of strategic planning for the future and became the driving force for re-structuring and re-branding. "My goal for RFR is to be able to continue with our original focus, which is face-to-face hospital visits to patients after surgery," she says, adding that in several countries only a phone service is offered.

She is currently working on a new fundraising concept to market RFR and put them on the map. "Bowling for Breast Cancer" will be the catchy name of the campaign and she has already set the ball rolling by approaching Bowls SA with a view to partnering with them in this venture. You can visit their Facebook page at www.facebook.com/Reach4RecoverySA for more photos and videos of the event.



The beautiful crystal Awards were donated by Innovative Glass, Johannesburg.

Lenasia Cancer Society promotes awareness of male cancers

The Lenasia Cancer Society held a meeting during August to promote awareness of men's cancers. Duke Mkhize of CanSurvive Cancer Support was one of the speakers. The organisation can be contacted at 011 854 3230



PinkDrive visits Northern Cape districts

PinkDrive and its brother campaign, More Balls Than Most, visited numerous communities in the Northern Cape during August.

The team delivered free breast cancer, cervical cancer, prostate and testicular cancer screening and education to 833 people in this province. Community visits included Kimberley, Upington, Onseepkans, Pofadder, Aggeneys, Garies and Vredendal. Services included mammograms, pap smears, PSA Screening, education regarding these diseases and general health messaging. Their nurses paid visits to numerous high schools where they provided education on breast health and demonstrations how to do a clinical breast examination. The team had the privilege of distributing re-usable sanitary towels thanks to Dignity Dreams to high schools in the areas. The scholars were very grateful for the donation as, for many of them, sanitary towels are a luxury that they cannot afford.

The realisation of how desperate communities are for the services PinkDrive and More Balls Than Most have to offer, together with the lack of facilities, confirms why they do what they do.

Statistics for this outreach:

Mammograms: 172

Clinical breast examinations: 354

PSA screening: 128

Pap smears: 166

Referrals: 13

From these stats it can be taken that their services made an impact in this province and they are convinced that our message of "early detection" touched and saved lives!

PinkDrive would sincerely like to thank the sponsors who made this trip possible: Vedanta, Black Mountain Mining, Roche, Caltex and Northern Cape Marketers, Futurelife, Kumala, aQuelle and Coca-Cola.



How to weigh up the benefits and risks of treatment ...and why it's important that you do

Do clinicians have accurate expectations of the benefits and harms of treatments and screening tests?

A new study in JAMA Internal Medicine found that a systematic review of 48 studies (13 011 clinicians), researchers found that clinicians rarely had accurate expectations of benefits or harms, more often underestimating harms and overestimated benefits. Among the findings, obstetricians and neurologists underestimated the risk of birth defects from anti-epileptic drugs and GPs overestimated the benefit of prostate cancer screening. Transplant surgeons were biased towards an inaccurately low estimate of graft failure and all types of doctors were unaware of the risk of radiation exposure from imaging.

What do these findings mean for patients? Inaccurate clinician expectations of the benefits and harms of interventions can profoundly influence decision making and the standard of care patients receive. Patient activist, blogger, and author of the upcoming book "Heart Sisters: A Survivor's Take on Women and Heart Disease" (Johns Hopkins University Press, November 2017), Carolyn Thomas, believes this to be "a consistently systemic issue for patients, too: most believe medical interventions will help more/harm less than they actually do". It's a wake-up call for patients who have a critical role to play in understanding and weighing up benefits and risks for ourselves, in order to get better treatment. And it's a further reminder of the importance of shared decision making to reach a healthcare choice together, as opposed to clinicians making decisions on behalf of patients.

However, understanding the risks associated with a treatment is not necessarily straight-forward. The challenge for busy clinicians is that there isn't always the time to read and digest the latest research to inform their practice. Medical commentator, physician, and cancer survivor, Elaine Schattner, believes that because medical knowledge changes so rapidly it's hard for clinicians to keep pace. "This may be especially true in oncology," she points out, "as patients become expert in their own conditions and needs, they may prefer to look up information on their own, and share their findings with their physicians."

A lengthy article published recently in ProPublica, examines what it calls "an epidemic of unnecessary and unhelpful treatment" requested by patients and delivered by doctors, even after current research contradicts its practice. "It is distressingly ordinary for patients to get treatments that research has shown are ineffective or even dangerous", writes David Epstein. "Some procedures are implemented based on studies that did not prove whether they really worked in the first place. Others were initially supported by evidence but then were contradicted by better evidence, and yet these procedures have remained the standards of care for years, or decades." Epstein points to a 2013 study which examined all 363 articles published in The New England Journal of Medicine over a decade - 2001 through 2010 - that tested a current clinical practice. Their results, published in the Mayo Clinic Proceedings, found 146 studies that proved or strongly suggested that a current standard practice either had no benefit at all or was inferior to the practice it replaced. Of course, this is not to say that myriad treatments don't indeed improve and save lives, but it's important to ask questions and do your own research before making a decision on which treatment is the best for you.

Start by asking your doctor to explain all the treatment options open

to you, including what would happen if you do nothing. Recognise that all treatments are inevitably associated with some risk of possible harm. Ask your doctor to quantify that risk beyond a purely descriptive term, such as "low risk" (what your doctor considers a small and acceptable risk may be unacceptable to you).

Next, do your own research. In order to make an informed decision, you will need to gather reliable information on which to base your choice. Fully exploring the risks and benefits of treatment involves doing your own evidence-based research (using evidence from medical studies that have looked at what happens to many thousands of people with your condition). In a previous article, I shared some helpful guidelines for assessing medical information. Most media reports about the benefits of treatments present risk results as relative risk reductions rather than absolute risk reductions, so you will need to understand the difference. Absolute risk of a disease is your risk of developing the disease over a time period. We all have absolute risks of developing various diseases such as heart disease, cancer, stroke, etc. Relative risk is used to compare the risk in two different groups of people. For example, research has shown that smokers have a higher risk of developing heart disease compared to non-smokers. Ask your doctor to differentiate between absolute and relative risk. Check out the NNT website which provides non-biased summaries of evidence-based medicine. "NNT" stands for a statistical concept called the "Number-Needed-to-Treat" – as in "How many patients need to be treated with a drug or procedure for one patient to get the hoped-for benefit?" The core value of the NNT is its straightforward communication of the science that can help us understand the likelihood that a patient will be helped, harmed, or unaffected by a treatment. It provides a measurement of the impact of a medicine or therapy by estimating the number of patients that need to be treated in order to have an impact on one person. Because we know that not everyone is helped by a medicine or intervention -some benefit, some are harmed, and some are unaffected, the NNT tells us how many of each.

You may also want to hear about what other people with your condition have chosen to do and what their experience has been. But remember that just because something has/hasn't worked for someone else, it doesn't mean it will/won't work for you. Orthopaedic surgeon, Dr Nicholas DiNubile, recommends patients ask their doctors, "If this were you, or one of your immediate family members, what would you do and/or recommend?" While this may be useful, you must ultimately decide what benefits and risks are important to you. Can you tolerate the side-effects? Are you happy with the way the treatment is administered? Would you find it stressful to live with the risk of any serious side effects, even if the risk is small? What matters is whether you think that the benefits outweigh the risk of any side effects. Everyone is different. The treatment recommended for you may not be the best treatment for your particular lifestyle. Being an advocate for your own health care involves asking lots of questions, doing your own research, and making your preferences known to your doctor. By doing this, you will be better informed and in a stronger position to get the treatment that is right for you.

Originally published on the Patient Empowerment Network website <https://www.powerfulpatients.org/2017/02/24/how-to-weigh-up-the-benefits-and-risks-of-treatmentand-why-its-important-that-you-do/>

Breast Health Foundation's Bosom Buddies in action

Thank you to The Shuffling Walking Team, the community of Bedfordview and all the supporters that came out in support of breast cancer fighters and survivors. It is because of your backing that we can move forward at the Breast Health Foundation and care for those affected by breast cancer.

The Shuffling Walking Team have managed and organised the event for the last six years, starting with 200 entries and have now grown to over 6000 entries in 2017.



Top: Prof Carol-Ann Benn (centre) opened the race hosted by The Shuffling Walking Team Bedfordview. She was backed by the Bosom Buddies, an initiative of the Breast Health Foundation.

Bottom: Maria Luz Da Silva (centre), breast cancer survivor and founder of The Shuffling Walking team along with the best dressed from the race day.

Image credit: Photo Maria Studio <http://www.photomaria.co.za/>



PSA and male cancer support group

Monthly support groups are held at the Boardroom at MediClinic, Constantiaberg, Plumstead

19 September 17:45 – 19:00

The speaker will be Dr Greg Hart of GVI Oncology

For more information contact:

Contact: 076 775 6099

Email: info@can-sir.org.za. Web: www.can-sir.org.za

Our grateful thanks to Medi-Clinic for providing a home for our activities and refreshments for our members.

It is much appreciated by us all.

SUPPORT AND INFORMATION

Thursday 14 September 2017, 14:00

We know how challenging a cancer diagnoses of a loved one can be for caregivers therefore we want to invite you to our next support group meeting 14:00 on

Come and share practical information, inspiration, and support with others that is going through the same. Sometimes what we need most is simply to be with other people who understand what we're going through.

Elana Botes (Social Worker in Private Practice) and Loreine Saunders (Medical Dietitian) will answer questions and assist you with this challenging role you need to fulfil.

For more info or to book your seat contact Oncology Social Worker Engela van der Merwe on 044 884 0806 or at engela.vandermerwe@cancercare.co.za

Outeniqua, George Group

Venue: CancerCare Boardroom,
3 Gloucester Avenue, George

cancercare
by GVI Oncology

A RACE AGAINST TIME:

The tale of the travelling stem cells

Over the past 25 years, the South African Bone Marrow Registry (SABMR) – the only registry in South Africa that supports an active unrelated donor match and transplant programme – has helped save the lives of hundreds of patients with life-threatening blood diseases.

Currently, approximately 30 times a year, couriers travel to fetch stem cells from anonymous overseas donors, delivering them to South African patients awaiting bone marrow transplants. Timing is everything when a patient needs a bone marrow transplant to survive and the journey of stem cells for transplant is planned like a military operation. From searching for the right tissue match – finding someone who is like an identical twin found in the general public – to co-ordinating the collection and delivery of stem cells, the SABMR leaves nothing to chance.

The first hurdle: Finding a matching donor

The SABMR's mission is to find matching unrelated bone marrow donors for critically ill South Africans who need a transplant to live but who do not have a match in their family. This represents the majority of patients – over 70% – living with disorders or illnesses such as leukaemia. Stem cell transplants can help patients recover from these serious maladies and live a long and healthy life.

Since the chance of finding a matching donor for a patient is approximately one in 100 000, identifying a suitable match is a complex process that can take weeks, or even months, to find. With only close to 74 000 registered donors in South Africa, the SABMR has partnered with donor registries in 56 countries worldwide to increase the chance of finding the perfect match for local patients.

Andrew Melck, 27, is a representation of the 70% of patients who rely on finding a match from an unrelated donor. Andrew was diagnosed with leukaemia in September 2015. The SABMR conducted a search across local and international databases but a match was not found in South Africa. Just two months after Andrew's diagnosis, the SABMR found a 10/10 match on the German database.

Comments Andrew: "The thought that a donor may not be found is one that slowly wears down your energy and emotions, leaving you open to worry and frustration. I was ecstatic and relieved when I heard the news that an international donor had been found."

The second hurdle: transporting the stem cells, often from overseas, to the patient

Once a match is found, the SABMR coordinates the transport of the collected cells to the patient's bedside in a transplant centre in South Africa. The bag of life-saving stem cell fluid – live human tissue – must be transported by a personal courier and arrive within 72 hours of the start of collection to remain effective for transplant. It is kept in a small, cool, temperature-monitored hamper and closely watched to ensure its safety. Couriers may not take alcohol or sleeping pills on the plane and must keep the container within sight at all times, taking it with them wherever they go.

SABMR Assistant Harvest Co-ordinator, Jane Ward, is one such courier who has travelled locally and across the world to courier stem cells from donors to the bedsides of patients in South Africa.

As a seasoned courier, Jane knows the importance of delivering stem cells on time.

Jane elaborates: "As couriers, we are told that we can only pick up the hamper at a certain time, since harvesting of the cells needs to take place and necessary blood counts need to be done. The timing of these processes can often be tight."

On one occasion, while travelling from Sheffield, England to Manchester Airport to catch her connecting flight to Heathrow Airport, Jane found herself in a taxi stuck in traffic for more than an hour. Out of his own will, the taxi driver decided to risk getting points deducted from his driver's licence to get Jane and the cells to the airport on time. Upon arriving at the airport, and with less than an hour until boarding time, Jane needed to make her way through security. The hamper carrying the cells cannot be X-rayed as this can destroy the cells. Thus, in order to prevent this, couriers have to be prepared and follow strict security protocol. After waiting for more than 20 minutes while the security manager verified her documents, Jane boarded the flight with minutes to spare.



Jane Ward, courier.

Despite the challenges presented by international collections, most courier trips are uneventful. The moment the stem cells reach the transplant centre, couriers are met with the feeling of relief and satisfaction that their job is done. Jane adds: "It is a great privilege to be a part of potentially giving someone a second chance at life."

The SABMR's role in helping save the lives of patients in need of a bone marrow transplant is an intricate one that is carried out with the utmost care. The selfless acts of couriers like Jane bring hope to patients like Andrew for a second

lease on life.

Andrew concludes: "Words can't describe the gratitude one has for the people involved in providing you with a chance of survival. On a mission to deliver the cells from the unselfish donor, the courier takes part in a race against time and is often faced with immense challenges. Their determination saves lives and we, as patients, are eternally grateful for this."

For further information on the South African Bone Marrow Registry (SABMR), contact +27 (0) 21 447 8638 or visit their website www.sabmr.co.za.

VISION E-NEWSLETTER

VISION is produced for CanSurvive Cancer Support and is an e-newsletter for cancer patients and caregivers everywhere and with any type of cancer.

Please send details and pics of any support meetings and cancer related events anywhere in South Africa so that we can include these in the newsletters.

Your comments, articles, and letters submitted for publication in VISION are always welcomed and can be sent to the Editor at: cansurvive@icon.co.za.

Subscription to the newsletter is free - just email us.

Enquiries: 062 275 6193

Light in the dark

Her name is Joann; she has cancer. As that disease goes it is not much, probably curable, one of those "if you have to get cancer, this a good one." Still, she sits across from me, her skin pale, eyes tight and she rhythmically grasps her cold, moist hands. She fails to gain any comfort from the knowledge that she is going to be OK. Why? I have not told her.

His name is Eric; he has cancer. As that disease goes it is bad, incurable, one of those "if you have to get cancer, do not choose this one." He sits across from me, rocking slightly in the chair, making fleeting eye contact and tightly gripping both knees. He fails to gain any comfort from the knowledge that there is still a lot we can do and that we will control his pain and I will take care of him. Why? I have not told him.

Recently, a new patient sat down with me. She did not know my style or my belief in direct patient empowerment. She felt the need to educate me on how she wished to be treated. After I finished taking her history and doing a careful exam, but before I began teaching her about diagnosis, therapy and prognosis, she looked me in the eye and said. "Doctor, whatever you do, you have to tell me every-

CanSurvive

CANCER SUPPORT

Let's talk about cancer!

Join us at a **CanSurvive Cancer Support** group meetings for refreshments, a chat with other patients and survivors and listen to an interesting and informative talk.

Upcoming meetings:

SOWETO, HapyD, 1432 Buthlezi St. Jabulani - 16 September 09:00

CHARLOTTE MAXEKE Radiation Department, Level P4 - 20 September

CHARLOTTE MAXEKE Radiation Department, Level P4 - 4 October

PINEHAVEN, Pinehaven Hospital - 7 October 09:00 (to be confirmed)

PARKTOWN Hazeldene Hall (opposite Netcare Parklane Hospital) - 14 October 09:00

Enquiries: 062 275 6193

or email cansurvive@icon.co.za

www.cansurvive.co.za

www.facebook.com/cansurviveSA

The Groups are free and open to any survivor, patient or caregiver.

James C. Salwitz, MD

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>



thing. You have to be honest with me. I need to know, so I will not be scared."

Doctors spend a lot of time lying to people. Perhaps, that is the wrong word. Doctors spend a lot of time holding back the truth and doling out bad news in small pieces. We may plan to eventually tell the complete story, but time passes, new events interfere and our patients never gain a full grasp of what is happening. We do this out of love and compassion, not wishing to cause pain or overwhelming anxiety. Nonetheless, by leaving much unsaid and in the dark, we cause fear and amplify suffering.

There are two basic facts we need to understand and incorporate into medical practice. The first is that most people are extremely strong and capable of coping with the worst medical news. It is not that anyone will be thrilled to learn about a dire prognosis, but with support and time, we can handle it. Doctors and families often underestimate the inner strength of patients. We are so concerned that someone we care for will give up, we give up on them.

The second is that people need to know the truth so that they can concur fear and plan their lives. When the unknown is wrapped in sterile halls, sharp needles, stern physicians and stamped with the word "cancer," terror has no stronger name. Given a complete picture of what is happening, patients and families can organise their emotions and plan lives to cope with what is to come. In the absence of an understanding of reality all they have is thin hope, and that makes for a flimsy blanket.

Now, to be clear, the communication I am prescribing is not:

"You have cancer. You are screwed. Get your affairs in order."

I am talking about systematic, compassionate, supportive education:

This is what we have found. Do you understand? This is the diagnosis. Do you understand? This is the likely prognosis. Do you understand? These are the treatment alternatives. Do you have any questions? In addition, where reasonable, it is vital to include the extremely rare statement; "you do not have to do anything, it is up to you."

A back and forth patient conversation which, depending on the patient's comprehension and need, may occur over several meetings. The patient needs to be informed and kept in the loop regarding changes, both good and bad. The doctor is the learned advisor; the patient is in charge.

The truth shall set you free. This is freedom from the unknown, freedom from pain and freedom to live your life as you wish. Doctors, caregivers and families must empower each patient with the knowledge to guide their own futures. With compassion, they can walk through the blackest night. It our job to light the darkness.



Priority area #6: Psychosocial care

Statistically, more than half of all cancer patients develop significant psychosocial adjustment problems. The emotional stress can be overwhelming and no one should have to manage it alone.

The facts

Fear of death, disruption of life plans, changes in body image and self-esteem, changes in social role and lifestyle, and financial concerns are all realities in the lives of people diagnosed with cancer. In fact, at least a quarter suffer major depression which, unless treated, can impact negatively on their quality of life.

That's not in question. But a major issue for psychosocial oncology is how we get to a place where we rapidly, and in a standardised way, identify and appropriately care for patients and families in need of specialised psychosocial and rehabilitation services.

The issue of screening for distress is gathering momentum internationally; in 2011 delegates at the meeting in China of the Union for International Cancer Control (UICC) voted to endorse the International Psycho-oncology Standard of Care document, which recognised distress as the sixth Vital Sign.

South Africa needs to urgently rethink its lack of commitment in this area, especially in light of data that shows distress is a risk factor for non-adherence to treatment.

Ultimately it also impacts on patients' decision-making, which can impact negatively on the oncology team as it manifests in increased visits to doctors and the emergency room, a situation South Africa can ill-afford.

Patients – and their families and carers – deserve the best outcomes possible, and this requires the inclusion of systemic psychosocial care in the continuum of cancer care.

So what do we need?

- ❑ A general acceptance of the value of psychosocial care for cancer patients.
- ❑ A strategy to ensure sufficient oncology social workers, trained counsellors and patient navigators throughout the country.
- ❑ A focus on the problems presented by language barriers.
- ❑ An acknowledgement that families and carers need significant support.
- ❑ Buy-in from NGOs and communities to help meet the need.
- ❑ Training in psychotherapy techniques for nurses, clinicians and radiotherapists.

We cannot achieve this without:

- ❑ Psychosocial training programmes that allow for screening for distress and psychosocial needs.
- ❑ Government commitment to formulate a treatment plan to address these needs, and to implement it.
- ❑ Partnerships with NGOs, civil society and communities to determine workable strategies, in line with South Africa's constrained resources, to ensure patients are referred to services as and when needed for psychosocial care.

How can we meet the challenge?

Challenge 1: Training programmes

It's common cause that the remarkable advances in biomedical care for cancer have not been matched by achievements in providing high-quality care for the psychological and social effects of cancer.

Without social workers, oncology nurses, doctors and others involved in the continuum of cancer care receiving the required training in psychosocial care, this cannot be addressed.

Such training should focus on the core concepts of patient-centred, supportive-expressive, cognitive and dignity-conserving care.

Screening tools that have been found to be feasible and effective in reliably identifying stress and the psychosocial needs of patients include the ultra-short method known as the Distress Thermometer.

Among the primary oncology team members – oncologist, nurse and social worker, it is critical for at least one team member to be familiar with available mental health, psychosocial and chaplaincy services.

Challenge 2: Government commitment

One of the biggest challenges is the fragmented healthcare system, with cancer patients receiving care from several service providers in multiple settings. With good communication, this system can and should provide every patient with the care they need – although this mostly fails to work in practice.

Mental healthcare routinely takes a back seat when it comes to allocation of resources, and it's time for the government to step up and recognise the benefits of psychosocial care for cancer patients.

The Department of Health and the Department of Social Development need to jointly recognise the need for cancer patient-navigators in South Africa, offering culturally-sensitive support and guidance to patients.

Without that commitment, it will be impossible to develop such patient navigation interventions, which work to reduce or even eliminate cancer health disparities.

Challenge 3: Partnerships

Partnerships with NGOs, civil society and communities are essential to help fill the gaps in resource-poor settings, with a vital role to play in establishing interventions such as patient navigator programmes. Patient-navigators can break through literacy barriers, build trust, reduce fear, and support the improvement of patient-provider communication amongst cancer patients, their carers and their families. Advocacy is needed to ensure pressure is maintained on the public sector health services to provide the vital supportive care throughout the trajectory of care.

NGOs and other civil society groups have proved their worth in the field of HIV/Aids treatment and care in South Africa, and now the same needs to be done for cancer.

Other than working as agents of change, these organisations have a vital role to play in educating cancer patients about their rights, increasing health awareness and literacy, encouraging volunteerism, and also driving public campaigns and community outreach.

Patients needing palliative care also need psychosocial support services, which are currently sadly lacking. Patients are not routinely referred to hospice care when they are discharged from state hospitals, which leaves them vulnerable as they navigate their end-of-life journeys without the proper community care and discharge support and services. The plight of rural and socio-economically vulnerable cancer patients is particularly desperate, and the emotional impact on their families is profound.

CALENDAR

September 2017

- 16 CanSurvive Jabulani Group at HapyD, 1432 Buthelezi St.
 18 Cancercare Support Group, Rondebosch Medical Centre, "What about diet, supplements, alternative treatment etc."
 19 Can-Sir Malecare Support Group, Mediclinic Constantiaberg, Plumstead, Cape Town, 17:45 – 19:00
 20 CanSurvive Charlotte Maxeke Group, Radiation Floor P4.
 20 CancerSupport@Centurion support Group at Netcare Unitas Hospital, Centurion at 16:00
 21 Cape Gate Oncology Group, Oncology Centre 10:00. "Cancer and pain management".

October 2017

- 4 CanSurvive Charlotte Maxeke Group, Radiation Floor P4.
 4 Cancercare OuteniquaSupport Group, GVI Boardroom,3 Gloucester Ave. George 10:00 - 12:00
 7 CanSurvive Cancer Support West Rand Group, Netcare Pinehaven Hospital, 09:00 (to be confirmed).
 7 Wings of Hope, Netcare Auditorium, Sandton. 10.00
 7 Bosom Buddies Support Group, Hazeldene Hall, Parktown at 09:30 for 10:00
 14 CanSurvive Cancer Support Parktown Group, Hazeldene Hall, Parktown 9:00
 17 Can-Sir Malecare Support Group, Mediclinic Constantiaberg, Plumstead, Cape Town, 17:45 – 19:00
 18 CanSurvive Charlotte Maxeke Group, Radiation Floor P4.
 18 CancerSupport@Centurion support Group at Netcare Unitas Hospital, Centurion at 16:00
 21 CanSurvive Jabulani Group at HapyD, 1432 Buthelezi St.
 22 Avon Justine IThemba Walkathon, Marks Park, Johannesburg
 26 Cape Gate Oncology Group, Oncology Centre 10:00. "Breast cancer and treatments".
 28 CANSA Breast Walk, Emerald Casino, Vanderbijl Park.
 30 Cancercare Support Group, Rondebosch Medical Centre, "Stress release as part of healing"

November 2017

- 1 CanSurvive Charlotte Maxeke Group, Radiation Floor P4.
 1 Cancercare OuteniquaSupport Group, GVI Boardroom,3 Gloucester Ave. George 10:00 - 12:00
 3 CanSurvive Bowls Challenge Match at Randburg Bowls Club. Starting 12:00.
 4 CanSurvive Cancer Support West Rand Group, Netcare Pinehaven Hospital, Krugersdorp 09:00 (to be confirmed)
 11 CanSurvive CELEBRATION OF LIFE, Sunnyside Park Hotel, Parktown 8:00 for 8:30
 15 Reach for Recovery Group meeting 13:45 Lifeline offices,2 The Avenue, Cnr Henrietta Street, Norwood
 15 CanSurvive Charlotte Maxeke Group, Radiation Floor P4.
 15 CancerSupport@Centurion support Group at Netcare Unitas Hospital, Centurion at 16:00

CONTACT DETAILS

CanSurvive Cancer Support
 Parktown and West Rand Group ;
 Contact: 062 275 6193 or cansurvive@icon.co.za
 Charlotte Maxeke Group: Contact Duke Mkhize 0828522432
 Jabulani Group: Contact Sister Bongwiwe Nkosi: 0835760622
 CancerCareSupport Group, 4th Floor, Rondebosch Medical Centre. Contact: linda.greeff@cancercare.co.za or phone 0219443700 for more info
 CancerCare Cape Gate Support group: 10h00-12h00 in the Boardroom, Cape Gate Oncology Centre. | Contact: Caron Caron Majewski, 021 9443800
 CancerCare Outeniqua, George Support Group. Contact: Engela van der Merwe, 044 8840705, engela.vandermerwe@cancercare.co.za
 Cancersupport@centurion: Marianne Ambrose 012 677 8271(office) or Henriette Brown 072 8065728
 Bosom Buddies: 011 482 9492 or 0860 283 343, louise@mybreast.org.za
 Venue: Hazeldene Hall, 13 Junction Ave, Parktown, Johannesburg. www.bosombuddies.org.za.
 More Balls than Most: febe@pinkdrive.co.za, www.pinkdrive.co.za, 011 998 8022
 PinkDrive: www.pinkdrive.co.za, Johannesburg: febe@pinkdrive.co.za, 011 998 8022;
 Durban: Janice Benecke: 031 201 0074/082 557 3079 janice@pinkdrive.co.za
 Cape Town: Ebrahim Osman: 021 697 5650 ebrahim@pinkdrive.co.za
 Prostate & Male Cancer Support Action Group, MediClinicConstantiaberg. Contact Can-Sir: 079 315 8627 or Linda Greeff: linda.greeff@cancercare.co.za, phone 0219443700
 Wings of Hope Breast Cancer Support Group 011 432 8891, info@wingsofhope.co.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
 Netcare Clinton Support Group 10:00 Netcare Clinton Oncology Centre, 62 Clinton Rd. New Redruth. Alberton. Second Friday each month.
 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 or 072 7633901. Meetings: Lifeline offices, 2 The Avenue, Cnr Henrietta Street, Norwood
 Reach for Recovery (R4R) : West Rand Group. Contact Sandra on 083 897 0221.
 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, Jenny Caldwell, 072 248 0008.t
 Reach for Recovery: Harare, Zimbabwe contact 707659.
 Breast Best Friend Zimbabwe, e-mail bbzfim@gmailcom
 Cancer Centre - Harare: 60 Livingstone Avenue, Harare
 Tel: 707673 / 705522 / 707444 Fax: 732676 E-mail: cancer@mweb.co.zw www.cancerhrc.co.zw

News in brief

Israeli procedure monitors cancer patients without radiation

Doctors at Jerusalem's Hadassah Medical Centre have developed a new method to monitor tumours without injecting patients with radioactive substances or exposing them to ionizing radiation.

The method, detailed in a study published recently in the *Nature Communications* journal, was developed by the director of the Centre for Hyperpolarised MRI Molecular Imaging, Rachel Katz-Brull, and her team at Hebrew University of Jerusalem.

Katz-Brull showed that by using magnetic resonance imaging, the nucleus of a phosphorous atom can alert doctors to suspicious acidity levels in the body, thereby revealing the possible existence of a tumour. The researchers used a special technique that allowed them to more easily identify the nucleus, enabling it to appear to "shine" 10 000 times brighter than normal.

"This diagnostic tool relates to the metabolic activity of the cells in a tumour or other in other tissue that may be suspicious," Katz-Brull said. "It may provide a better way to determine whether tumours are malignant or benign, and help test the efficacy of treatment."

The groundbreaking method makes it possible to avoid a biopsy or other invasive procedures to measure a tissue's acidity levels, and also to determine whether a tumour is malignant or benign without having the patients undergo unnecessary radiation or be exposed to radioactive materials.

<http://tinyurl.com/yc9uwdql>

Anti-inflammatory therapy can cut risk of lung cancer

In most clinical trials for cancer therapy, investigators test treatments in patients with advanced disease. But a recent cardiovascular secondary prevention study gave researchers an unique opportunity to explore the effectiveness of giving a drug to patients before cancer emerges. At the European Society of Cardiology meeting, Paul M. Ridker, MD, director of the Centre for Cardiovascular Disease Prevention at BWH, and colleagues presented findings from CANTOS (Canakinumab Anti-inflammatory Thrombosis Outcomes Study). In addition to their cardiovascular results, Ridker and colleagues shared that patients who received the anti-inflammatory therapy canakinumab had a marked reduction in the incidence of lung cancer and lung cancer mortality. In this high-risk population, death from cancer was reduced by half in the group of people who received the highest dosage of the drug.

"As an inflammatory biologist and cardiologist, my primary interest is in heart disease, but my colleagues and I were aware of experimental research indicating a connection between cancer and inflammation, and we recognised that our cardiovascular clinical trial could be the perfect place to explore this link," said Ridker. "The data are exciting because they point to the possibility of slowing the progression of certain cancers.

<http://tinyurl.com/ya6mj8d>

Robot-aided surgery now in Eastern Cape

The first robot-assisted surgeries to treat prostate cancer in the Eastern Cape were performed by Netcare Greenacres urologists Dr Hannes Brummer and Dr Johan Coetzee this week following the installation of the Da Vinci machine. Similar robotic systems have been installed at Netcare hospitals in Cape Town, Johannesburg and Durban.

Coetzee and Brummer have been training in South Africa and Europe to perform robot-assisted surgery.

Netcare hospital division managing director Jacques du Plessis said that after robotic surgery systems had been introduced in other provinces there had been an increased number of referrals from other provinces.

"We have now brought the technology and capacity for robotic-assisted procedures to the Eastern Cape. We identified a need for the intricate and highly complex interventions the Da Vinci Si system enables trained surgeons to achieve," he said.

Netcare Greenacres Hospital general manager Andre Bothma hailed the development and the benefits it would bring for patients with localised prostate cancer. It is also used for kidney and bladder cancer surgery. "The new technology will make it possible for trained specialists to offer our patients world-class prostate cancer treatment," he said.

Urologist and robotic surgeon Dr Gregory Boustead, consultant adviser to Netcare hospitals, said these surgeries were the gold standard in the treatment of localised prostate cancer in Europe and the US. The technology enabled surgeons to achieve greater surgical precision due to better visibility of the surgical site.

He said the first 500 robotic-assisted prostate surgeries at Netcare facilities had shown excellent results. He further explained that patients are only required to stay in hospital for two to three days and complication rates were very low.

Anti-inflammatory, anti-stress drugs taken prior to surgery may reduce metastatic recurrence

Most cancer-related deaths are the result of post-surgical metastatic recurrence. In metastasis, cells of primary tumours travel to other parts of the body, where they often proliferate into inoperable, ultimately fatal growths.

A new Tel Aviv University study finds that a specific drug regimen administered prior to and after surgery significantly reduces the risk of post-surgical cancer recurrence. These medications, a combination of a beta blocker (which relieves stress and high blood pressure) and an anti-inflammatory, may also improve the long-term survival rates of patients. The treatment is safe, inexpensive - two medications similar in price to aspirin - and easily administered to patients without contraindications.

The research was led by Prof. Shamgar Ben-Eliyahu of TAU's School of Psychological Sciences and Sagol School of Neuroscience in collaboration with Prof. Steven Cole of UCLA; Prof. Oded Zmora of Sheba Medical Centre, Tel Hashomer; Prof. Eran Sharon of Rabin Medical Centre, Beilinson; and Prof. Tanir Ellweiss of Kaplan Medical Centre. It was published in *Clinical Cancer Research*.

"We've taken an unconventional approach, deviating from the current medical dogma that refrains from intervening during the short

period surrounding a cancer surgery - no chemo, radio or immune therapy for at least three weeks before or after surgery," Prof. Ben-Eliyahu said. "Even within the medical establishment, we encountered some levels of disbelief and antagonism. But after conducting ample studies in animal models of cancer, and reviewing the medical literature, we came to the firm conclusion that maybe this is the most important period in the prevention of cancer recurrence."

For the study, 38 breast cancer patients at Sheba Medical Centre, Kaplan Medical Centre and Rabin Medical Centre were given a pharmacological treatment - Deralin (used to reduce blood pressure and anxiety) and Etopan (used to reduce inflammation) - five days before their surgeries, the day of their surgeries and five days after their surgeries. Blood and tumour tissue samples were then analysed using whole genome gene expression profiling to identify all the RNAs expressed in malignant cells and leukocytes.

"We found that the drugs were very efficient in reducing biomarkers of metastatic processes," Prof. Ben-Eliyahu said. "For example, we found that the drug treatment reverses EMT - the process that tumour cells go through to slip out of the primary tumour and enter another organ. It is a crucially important step in the metastatic process. We also looked at indices related to the immune system and were able to improve immune competence and reduce inflammation with the drugs."

<http://tinyurl.com/ybmnw8me2>

Using 3D animation to prevent chemotherapy mistakes

Artist Ryan Berardi got firsthand experience with chemo after being diagnosed with acute lymphoblastic leukaemia (ALL) at 17. He then combined his experience of cancer with his artistic talents to create a 3D animation that helps oncology nurses avoid giving patients the wrong chemo medications. If they make a mistake, the tool can help nurses see where they went wrong to prevent future mistakes.

"This study of anatomy, alongside my cancer treatment for leukaemia led me to develop a love for medicine and the human body," Berardi said in an interview with CURE.

Together with Dr. Fiona Hogg, a plastic surgeon consultant at Ninewells Hospital, NHS Tayside, he worked on the project.

The animation shows an image of the patient's hand during the infusion, and illustrates what is called an "extravasation." That happens when the chemotherapy leaks out of a vein and into the surrounding tissue. The animations also and goes over the symptoms and side effects. The animation also walks the health care provider through the stages of the "Flush-Out" technique, which is used to prevent tissue necrosis, or death.

<http://tinyurl.com/y94sj3a6>

Mushroom protein could be used in future leukaemia treatments

A protein found in the edible mushroom known as "shaggy ink cap" might be able to kill a type of leukaemia cell, new research suggests.

Coprinus comatus, also known as "shaggy ink cap" or "lawyer's wig," is a type of edible mushroom normally found in North America and Europe. Its habitat is usually meadows and grasslands, but it can also sometimes be found along gravel roads or on lawns in towns and cities.

It takes its common names from its white, shaggy appearance when mature, but also from the fact that it starts "dissolving" into a black, inky mass once it starts to decay, or soon after being picked.

This type of mushroom is already known for its nutritional value, as well as for its antioxidant and antimicrobial potential. Some studies have also variously linked Coprinus comatus elements with potential for HIV, prostate cancer, and ovarian cancer treatments.

Researchers from the University of Florida in Gainesville have now uncovered a new potential for a Coprinus comatus protein: killing a type of leukaemia T cell.

Dr. Yousong Ding, an assistant professor at the University of Florida, and his team looked at how Y3, a protein present in Coprinus comatus, binds with the LDNF glycan, which is a sugar molecule usually found in parasites. This activates a cell-signaling cascade that can programme a type of leukaemia T cell to commit suicide, the researchers explain.

Unique pathology atlas paves the way for personalised cancer treatment

A unique pathology atlas is now being launched and made available to researchers all over the world. It maps cancer-related genes and opens up a new route towards personalised cancer treatment.

The atlas project has been led by Professor Mathias Uhlén, SciLifeLab, KTH Royal Institute of Technology, in cooperation with colleagues from Uppsala University and elsewhere.

The new pathology atlas is a major step forward for the dream of personalised cancer treatment. The analyses of data from 8,000 patients and five million pathology-based images cover all human genes involved in all common forms of cancer (17 different cancer types) and show the consequences of their corresponding protein levels for patient survival.

The findings show great heterogeneity among individual tumours,



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which underlines the need for personalised treatment strategies and has major implications for survival. The analysis makes it possible to produce personalised genetic models to identify key genes involved in tumour growth.

"Our study demonstrates the power of 'big data' to change how medical research is performed," says Professor Uhlén.

The pathology atlas is now being opened up to researchers around the world.

"We are pleased to provide a stand-alone open-access resource for cancer researchers worldwide, which we hope will accelerate their efforts to find the biomarkers needed to develop personalised cancer treatments," says Fredrik Pontén, Professor of Clinical and Experimental Pathology at the Department of Immunology, Genetics and Pathology, Uppsala University.

<http://www.proteinatlas.org/pathology>

Human antibody bolsters cancer drug performance

Although generally effective, the cancer drug rituximab does not work for everyone. However, a new study finds that adding a specific human antibody to the medication might restore its cancer-killing capabilities.

Rituximab is not a chemotherapy drug, but rather a monoclonal antibody therapy that can be used either alone or alongside chemotherapy. This type of intervention uses antibodies, which bind to specific cells or proteins, thereby stimulating the patient's immune system to attack them.

Specifically, rituximab is an antibody against a protein called CD20, which occurs most commonly on the surface of immune B cells. Rituximab is useful in treating non-Hodgkin lymphoma and chronic lymphocytic leukemia; in these conditions, the cancer primarily affects the immune cells.

Rituximab is thought to work by using a number of mechanisms - for example, once the drug has bound to CD20, it forms a cap on one side of the cell, which draws proteins over to that side. When natural killer cells (a type of white blood cell) bind to the cap, they are more successful at triggering cell death, or apoptosis.

In short, rituximab helps the immune system to target and kill cancer cells more effectively.

<http://tinyurl.com/yat8gol3>

Using alternative medicine only for cancer linked to lower survival rate

Patients who choose to receive alternative therapy as treatment for curable cancers instead of conventional cancer treatment have a higher risk of death, according to researchers from the Cancer

Outcomes, Public Policy and Effectiveness Research (COPPER) Centre at Yale School of Medicine and Yale Cancer Centre. The findings were reported online by the Journal of the National Cancer Institute.

There is increasing interest by patients and families in alternative medicine as opposed to conventional cancer treatment. This trend has created a difficult situation for patients and providers. Although it is widely believed that conventional cancer treatment will provide the greatest chance at cure, there is limited research evaluating the effectiveness of alternative medicine for cancer.

While many cancer patients use alternative therapy in addition to conventional cancer treatments, little is known about patients who use alternative therapy as their only approach to treating their cancer.

"We became interested in this topic after seeing too many patients present in our clinics with advanced cancers that were treated with ineffective and unproven alternative therapies alone," said the study's senior author, James B. Yu, M.D., associate professor of therapeutic radiology at Yale Cancer Centre.

To investigate alternative medicine use and its impact on survival compared to conventional cancer treatment, the researchers studied 840 patients with breast, prostate, lung, and colorectal cancer in the National Cancer Database (NCDB) - a joint project of the Commission on Cancer of the American College of Surgeons and the American Cancer Society. The NCDB represents approximately 70% of newly diagnosed cancers nationwide. Researchers compared 280 patients who chose alternative medicine to 560 patients who had received conventional cancer treatment.

<http://tinyurl.com/y8e3hbo2>

Sickle Cell Disease drug gets FDA Approval

To have achieved a new means of treating a condition without a cure, for many in the medical field, the approval of a new medication that targets the (often debilitating) painful effects of the disease is a remarkable development.

For the past 25 years Dr Yutaka Niihara has had an invested interest in developing what the FDA (U.S. Food and Drug Administration) has now approved, a drug known as Endari (an L-glutamine oral powder made by Emmaus Medical, in Torrance, California, USA). Now the medication is set to effectively treat the effects of pain in patients five years of age and older and promote a better quality of life. To date, the average life expectancy of a person suffering from sickle cell disease has been between 40 and 60 years of age.

To date, this disease has no potential cure and treatment merely involves daily management of symptoms so as to minimise or alleviate risk for a myriad of possible complications. These include ulcers, splenic sequestration (a very painful and sudden enlargement of the spleen), neurological problems (stroke or seizures), blindness, pulmonary hypertension (elevated blood pressure in the arteries of the lungs) and pulmonary fibrosis (scarring of the lungs), gallstones, abnormal heart rhythms and various other heart-related problems.

The drug is not by any means a potential cure for sickle cell disease, but through trials, it has shown significant success in treating debilitating pain in particular.

Approval was based on a 48-week long clinical trial (followed by a 3 week-period of drug tapering) that noted a reduction in the need for hospitalisation where pain would normally be treated with injected anti-inflammatory medications (such as ketorolac) or a narcotic.

<http://tinyurl.com/y7uwxqe2>

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