



March/April 2017

... let us be the light at the beginning of your journey

An MS diagnosis led Professor George Jelinek's quest to stop history repeating

When George Jelinek was diagnosed with multiple sclerosis, the Australian medical professor was determined that he would not succumb to the disease that had destroyed his mother's life.

Sharon Bradley

August 30, 1981. He sat down on the bed and took her lifeless hand in his own. He bent over her and kissed her forehead. It was cold. He'd been told that she'd died during the night. The woman to whom he was closest in the world had gone, but the tears wouldn't come. For 16 years, he'd watched his mother succumb to a savage disease that, with its relentless purposefulness, had slowly robbed her of her vitality, her mobility, her independence.

First, she'd begun to drop things. Then she had difficulty walking. Gradually, walking sticks were replaced by a wheel chair, modifications to the family home were made. Finally, she had become bedridden, dependent on others for her every need. From time to time, he'd caught her looking at him with bitter tears of loss and longing in her eyes. In the end, she had summoned her meagre physical resources to commit one last supreme act of defiance: she had stockpiled the barbiturates she took to help her sleep and swallowed them all.

Her name was Eva Jelinek. She was just 58.

April 18, 1999. The late-afternoon sun was slanting through the trees outside the window, but as Professor George Jelinek listened to the words of the



George Jelinek 2016

neurologist sitting across the table from him, all he knew was a mounting sense of dread. It had all started a few days earlier, on the Tuesday morning after the Easter long weekend, as he began his first ward round of the day – a strange sensation in his left foot, as if his shoelace were somehow trapped inside his shoe, only it wasn't. By Wednesday, the toes of his left foot were numb and by Thursday, the sensation, or lack of it, had spread up the outside of his leg and around his backside. Something was wrong.

As the head of emergency medicine at Sir Charles Gairdner Hospital in Perth, Jelinek had no shortage of expert medical opinion to draw on, and an MRI had been hastily arranged. Now the neurologist was looking at the scans of Jelinek's brain and spinal cord and, on the basis of the lesions that he could see, was delivering his grim diagnosis. "I was looking out the window, thinking, 'Why is he going on about MS? That's what Mum had,' " says Jelinek. "But then the penny dropped – and I didn't

hear anything else for the rest of the consultation." He pauses. "It was as dark a day as it gets."

Somehow maintaining an appearance of outward calm, Jelinek drove home to break the news to his wife, Lee, mother to Sean, 14, Michael, 12, and Pia, 7. "She was incredulous," he remembers. "She called me her fearless leader because I'd always been so robust.

"I remember going to bed that night and waking up at about 3am to go to the bathroom. I was sitting on the toilet, looking through the window at the bougainvillea and the moon. It was just like any other night, but then suddenly I remembered that I'd just been diagnosed with this terminal, incurable, progressive, incapacitating disease. I started to cry. The future I'd carefully built for us was disintegrating."

Jelinek began a course of high-dose intravenous steroids to subdue the patches of inflammation in his central nervous system and broke the news to his three sisters, Iva, Gina and Suzette, and his younger brother, Peter. The siblings cried together and listened to him as he repeated, just as Eva had done, "I don't want to be a burden."

Jelinek was 45 and at the peak of a distinguished medical career. Australasia's first professor in emergency medicine, he was both the clinical director of the emergency department at Sir Charles Gairdner Hospital and head of the academic unit there, having founded Australia's first university department in the discipline. "I had a successful career," he says, "but I didn't know where to stop. I just kept

(continued on page 4)

CANCER INFORMATION & SUPPORT SOCIETY NEWSLETTER

Vol. 37 No. 2 March/April 2017

Editor: Don Benjamin

CISS Home Page:
www.ciss.org.au

Office hours:
Tuesdays { 10.00am - 1.00pm &
2.00pm - 4.30pm
Thursdays 10.00am - 1.00pm
or after by appointment

The Secretary
Cancer Information &
Support Society
6/56 Chandos St
St Leonards NSW 2065
Phone/Fax: (02) 9906 2189
email: ciss@iinet.net.au

IN THIS ISSUE

- P. 1 An MS diagnosis led Professor George Jelinek's quest to stop history repeating, by Sharon Bradley
- P. 2 Welcome to new members; Donations to CISS; Stress-Portrait of a Killer, DVD for loan; For Sale: Xylitol and Vitamin C; Free Psych-K for CISS members; Supplements for CISS members; DVDs for sale.
- P. 3 Overseas and Local News: Immunotherapy—the pros and cons; Recovering from Multiple Sclerosis; Dr Grygiel and low-dose chemo; Progress with Business Plan; AGM part 2
- P. 6 Body Code/Emotion Code Group Session; DVD “Stress Portrait of a Killer” now available for loan
- P. 7 CISS STORIES: Nick Di Camillo
- P. 9 History of Immune Checkpoint Inhibition, by Ralph Moss, PhD
- P. 10 Immunotherapy for Cancer — This Lauded Breakthrough Is Far More Dangerous Than Advertised, by Dr Mercola.
- P. 11 Report from the first part of the Annual General Meeting, 3 December 2016
- P. 12 What's Available from the CISS Office? Branches of CISS; Cancer Support Groups.
- INSERTS Notice of adjourned AGM; Proposed changes to CISS Constitution.

Birth Control for Grandma

The doctor who had been seeing an 80-year-old woman for most of her life finally retired. At her next check-up the new doctor told her to bring a list of all the medicines that had been prescribed for her. As the doctor was looking through these his eyes grew wide as he realised Grandma had a prescription for birth control pills.

“Mrs Smith, do you realise these are BIRTH CONTROL Pills?”

“Yes, they help me sleep at night.”

“Mrs Smith, I can assure you there is absolutely NOTHING in these that could possibly help you sleep!”

The old lady reached out and patted the young doctor’s knee....”Yes, dear, I know that. But every morning I grind one up and mix it in the glass of orange juice that my 16 year old granddaughter drinks. And believe me, it definitely helps me sleep at night”.

You gotta love Grandmas!!!

New members:

Michelle Chinnery, Debbie Keeble,
Sharon Kirley

Donations to CISS:

January: M.A. \$50; L.H. \$50;
February: S.G. \$50

DVD: Stress—Portrait of a Killer

Now available for loan from the CISS library.

Free Psych-K for CISS members

CISS members can receive Psych-K to identify and change negative belief systems free of charge. Ring the Office if you want to try it.

Supplements for CISS Members

Low Dose Naltrexone all strengths 1.5mg to 4.5mg
100 compounded capsules (Doctor’s prescription needed)
Look up “Low Dose Naltrexone” Homepage
Stabilised electrolytes of oxygen 50ml—\$15 (Chlorine Dioxide)
Visionary Health Compounding Chemist (02) 4969 5081

New email address for CISS

Please note that CISS has a new contact email address it is **ciss@iinet.net.au**

Once our new website is complete enquiries through the website will also be directed to:

info@ciss.org.au—Susie will answer; and
admin@ciss.org.au—Leonie will answer

For Sale

Champion Juicer

Perfect Condition Used once only

\$475

Phone Janet 07 3379 4623

For sale (at CISS Office)

Xylitol - Healthy substitute for sugar,
450gm—\$6.75

Vitamin C - 30% off : past best before date—\$17.

For Sale: **Norwalk 270 Juicer**

Good condition \$1,550.00

Water Ioniser Ion Farms HTH-5000 Gold. As new
4380 litres still to go on first filter \$1,150.00
Phone Trevor 0408 498 543

DVDs for Sale from the CISS Office

CISS Seminar “Cancer & Hope - Survivors share their Lessons” are available for \$29.50 plus postage for members or \$39.50 + postage for non-members

The Cancer Information & Support Society is an educational, non-profit organisation. The information in this newsletter is made available as a community service. It is not meant to be construed as, or in place of, medical advice or treatment by your physician. CISS does not diagnose, treat or prescribe for any human disease or physical condition. It does not prescribe or dispense medicine of any kind. CISS is not commercially affiliated with any product, therapy, company, publication or person and it assumes no responsibility for the use of the information described herein.

OVERSEAS NEWS

Immunotherapy: Pros and Cons

Some of the alternative cancer therapies CISS has outlined over the years include two potentially very beneficial therapies: William Coley's mixed bacterial vaccines and Lawrence Burton's Immuno-Augmentative Therapy (IAT) in the Bahamas. These are both part of the history of immunotherapy. The article by Ralph Moss on page 9 shows where these therapies fit in.

The extracts of an article by Dr Mercola on page 10 show the down side of immunotherapy when big drug companies get involved.



Don Benjamin, Editor

LOCAL NEWS

Recovering from Multiple Sclerosis

Multiple sclerosis has a lot in common with cancer and heart disease. For this reason it is not surprising that many people who try an alternative approach get better results. This issue describes a good example of this. (See page 1)

Dr Grygiel and low-dose chemo

As mentioned in our November Newsletter concerns were raised in mid-2015 about Dr Grygiel using chemotherapy doses that were half that recommended in the Guideline and using carboplatin instead of cisplatin for head and neck cancers. A NSW Health Department Inquiry had been set up in February 2016 to investigate the issue and had reported in September 2016.

The Australian on 25 February 2017 reported that when challenged over his decision to prescribe carboplatin instead of the guideline-backed cisplatin, Dr Grygiel had said authors of a meta-analysis suggested cisplatin appeared to be more toxic and may not be more beneficial for patients over 60 and patients with comorbidities.

Greg Kesby, president of the Medical Council of NSW, told a parliamentary committee inquiring into the flat-dosing "scandal" that Dr Grygiel's licence had not been cancelled.

The *Sydney Morning Herald* of 31 October 2016 reported that at the parliamentary Inquiry Dr Grygiel had said there was no evidence that the higher dose recommended in the guideline would have led to better outcomes for his patients. He believed that in many cases it would have led to a negative impact as it would have discouraged patients from

continuing treatment.

"I have devoted my entire career to the ethical treatment of cancer patients ... I very much regret the distress my patients have suffered as a result of the publicity surrounding these inquiries," he said.

This is the tip of the iceberg with most chemotherapy and arises out of the fact that clinicians drafting guidelines wrongly assume that a dose that shrinks tumours better and reduces recurrence must result in an improved survival. In many cases, because of the higher toxicity, the higher doses do more harm than good.

It is similar to the situation with radiotherapy where treatment is based on the unproven assumption that if it reduces recurrence it must extend life. This is rarely the case.

With surgery it took over 50 years to learn that "getting it all" did not help and only reduced the quality of life.

Progress with business plan

(a) Website structure

The website is currently still under construction but is working. We expect it to be completed in March. See the current one at www.ciss.org.au.

(b) Website content

The content for the website is being uploaded and it will be continually updated. This includes the growing *e-Library*. This will be a unique on-line library including documents related to various health areas.

(c) The App is also being developed.

(d) Campaign launch: This is still under discussion. Earliest date is now April.

Annual General Meeting—part 2

We held the first part of the AGM in December but because we now need

the accounts to be audited we adjourned the second part to be completed in March, including submitting the audited accounts and some amendments to the Constitution to bring it into line with the requirements of the new Regulation. We include with this issue the notice of the adjourned AGM, a summary of the Audited Financial Report and the proposed changes to the Constitution.

We have vacancies on the Committee. Contact the Office if you would like to be a member of the Committee.

(continued from page 11)

We see the same problem in other drug and vaccine research as well. Drug developers are primarily interested in finding out if the drug works. Is it effective? However, if a drug is effective in treating the ailment at hand, yet kills the patient, what has been gained?.....

References

1. PMLive.com March 8, 2016
2. FDA.gov, Breakthrough Therapies
3. *Annals of Oncology* 2010 Aug;21(8):1712-7
4. *New England Journal of Medicine* 2015 May 21;372(21):2006-17
5. *European Journal of Cancer* 2016 Jun;60:190-209
6. PMLive.com December 5, 2016
7. Juno Therapeutics
- 8,10 *STAT News* November 23, 2016
9. *CNN* November 23, 2016
- 11,12. *New York Times* December 3, 2016

Dr Mercola, December 20, 2016

http://articles.mercola.com/sites/articles/archive/2016/12/20/immunotherapy-for-cancer.aspx?utm_source=dnl&utm_medium=email&utm_content=art1&utm_campaign=20161220Z3&et_cid=D M128886&et rid=1805104053#_edn1

Farewell from CISS

We offer our loving thoughts to the family and friends of those members who have died in recent months

Geoffrey Hart

(continued from page 1)
 taking on more and more and thinking I could manage it all. But of course the person I didn't have time for was myself."

Today, George Jelinek's office is at the University of Melbourne's School of Population and Global Health in Carlton. There's no reception desk here and visitors are left to wander anonymous-looking corridors with an expression of beseeching enquiry on their faces until a kindly academic takes pity on them. In the end, a small placard on a door standing a little ajar reveals his whereabouts

When Jelinek steps forward to greet me, I'm struck by his physical vigour. At 62, he's tall and lean with the loping, long-legged gait of a teenager. His room is modestly furnished: there's a cupboard from IKEA, a rigorously tidy desk with a computer on it and, mysteriously, given that it's a blustery midwinter's day, what looks like a newly opened Christmas card. With his dusting of blond-grey hair and his deep, close-set eyes, he resembles, endearingly, a grown-up version of Charlie Brown. He couldn't possibly appear healthier if he tried.

Inviting me to sit down, Jelinek tells me that in those first, desperate days after his diagnosis, he called on his long-time friend and mentor, Perth gastroenterologist Dr Ian Hislop. The pair had first met decades earlier when Jelinek, as a young intern, did a 10-week attachment with the older man's team at Fremantle Hospital. The experience had been a transforming one. "It was Ian who showed me what you can do as a doctor when you connect to a patient on a personal level," he says. "It was very powerful."

The first major breakthrough was when I was able to breathe without pain. That first, wonderful, normal breath felt like a rebirth.

Now the old friends talked for two hours. "Every time I mentioned Mum, I found it almost impossible to speak without becoming tearful," Jelinek would write later. "It was clear that I was seeing my own illness and future through the filter of [her] disease and history."

Calmly, Hislop told Jelinek he was at a crossroads in his life and what he needed to do now, for the first time in years, was put himself first, starting with taking an indefinite leave of absence from work. "Then he asked me, 'How's your spirit?' and the question floored me,"

says Jelinek. "I realised I didn't even have the vocabulary to respond. I'd always thought of myself as happy – I had a good job, a nice house – but I couldn't seem to find real fulfilment. I was always grasping for more, somehow."

Jelinek had always been groomed for success. His parents, Eva and George Jelinek snr, had come to Australia, their baby daughter in tow, in 1949 as young Czech immigrants. They would go on to have four more children here; George, their first son, was their middle child. But it wasn't a harmonious household: "My father, an artist and musician, didn't drink or hit, but he was a shouter. If Mum hadn't got sick, it's probable the marriage wouldn't have lasted," he says.

Eva, a psychiatric nurse, steered the young George – who was bright – towards a career in medicine. One by one, the children left home as soon as they could, George fleeing at 17. George snr died nine years after Eva of heart disease. "But even after they were both long gone," says Jelinek, "I still had them both inside me, pushing me to continue achieving. It was the classic immigrant dream, after all."

For six weeks after his diagnosis, Jelinek holed up in his study at home. His brother, Peter, had casually mentioned in an email that a mate's wife in Bunbury had been taking gamma linolenic acid (GLA) as a supplement for her MS for a decade or so and hadn't had a single flare-up. "I entered 'GLA' into PubMed [an online archive of medical literature] and cross-referenced it with MS. A few papers came up straightaway that showed that people with MS who took it did indeed experience fewer relapses. I thought that was odd: when I'd asked the neurologist if there was anything I could do, he'd told me to just go home and wait. 'When you get sick, come back,' he'd said."

Jelinek discovered that GLA is a plant-derived essential fatty acid with the ability to dampen the body's inflammatory response, which goes into overdrive when an autoimmune disorder, such as MS, is active. Then something amazing happened. When he entered "fatty acids + MS" into PubMed, a long, shimmering thread of golden, evidence-based research, stretching from the 1940s to the 1990s and meandering across the dense paragraphs of text over which

he now pored, suddenly came sharply into focus.

Over the course of 34 years, an Oregon neurologist, Professor Roy Swank, had followed the health outcomes of 144 people with MS whom he'd placed on a diet that was very low in saturated fat. Many of them couldn't stick to it, which gave him a good basis for comparison. The results, published in *The Lancet* in 1990, showed overwhelmingly that the "good dieters" fared very well, the vast majority of them still active and relatively unscathed by the disease by the end of the trial. The diet defaulters, on the other hand, suffered flare-ups and a steady decline into disability. "Suddenly I had hope," says Jelinek.

But why had Swank's research been buried? "Thirty-four years is a long time," explains Jelinek. "By the time he finished the study, the world was in a new era of medical research. Some questioned his 1940s methodology, dismissed his findings and now modern neurology doesn't even pay lip service to him. It upsets me because he was well ahead of his time."

Jelinek came across another study, carried out by the Belgian School of Public Health in 1995, suggesting that geographical location had a direct bearing on the incidence of MS. Why was there relatively little MS in equatorial countries, where it's sunny and warm, and more and more of it the further north and south one travelled towards the poles? The answer was exposure to sunlight, which prompts the body to manufacture highly protective vitamin D.

Within two months, pulling together buried, but excitingly relevant strands of cross-disciplinary research, Jelinek had formulated a personal manifesto for wellness. "I typed up a document on the computer called *My Formula* and stuck it on the fridge door, and every time I walked by I'd sort of reach out and touch it like it was a rabbit's foot. I'd worked out how I was going to live." He'd also begun daily injections of a disease-modifying drug called Copaxone.

Ian Gawler, founder of the Yarra Valley-based Gawler Cancer Foundation, remembers giving a presentation at Sir Charles Gairdner Hospital towards the end of 1999. "Afterwards, this very humble person approached me and

(continued on page 5)

(continued from page 4)

asked me if I'd be interested in taking a look at a manuscript he'd just written. It was called *Taking Control of Multiple Sclerosis* [retitled a more emphatic *Overcoming Multiple Sclerosis* in 2006]. Struck by his manner, I said yes. Well, when I got back home and started reading it, I found it captivating. It was one of the best self-help books I'd ever read and of course it was based on the dual benefit of personal experience and his extraordinary capacity as a researching academic physician. I was so impressed that I wrote the foreword.

"I was aware George was applying the same principles to MS management as I was in the work I was doing with cancer patients," he continues. "We help them adopt a lifestyle approach that's highly anti-inflammatory and regenerative. With MS being a chronic degenerative disease like cancer or heart disease, it made sense to me that it would respond to the same approach. I suggested to George that we combine our expertise and organise some live-in retreats."

Linda Bloom was an early participant. In 2002, she was a 28-year-old psychologist living in Melbourne's St Kilda and studying for her master's when she suddenly started to experience numbness and tingling throughout her body, dizziness so severe she couldn't lift her head off a pillow, and an absolute, poleaxing fatigue. A tight, clamping sensation around her chest – known as the "MS hug" – made simply breathing an ordeal. "I was lost," says Bloom. "Overnight I went from being a strong, independent woman to a terrified invalid who needed help doing everything."

Bloom's sister, a doctor, had come across a copy of Jelinek's book and read it to her. And with nothing left to lose, Bloom began to follow the formula inside its pages. "I noticed small improvements after about a month, but I think the first major breakthrough was when I was able to breathe without pain. That first, wonderful, normal breath felt like a rebirth."

Her health continued to gradually improve as she embraced the Jelinek protocol: a diet rich in seafood, fresh fruit and vegetables. She took daily doses of flaxseed oil and vitamin D. She meditated. Four years later, she was well enough to climb all 4096 metres of Mt Kinabalu, one of south-east Asia's highest peaks, with her new boyfriend. "I trained hard for it by walking,

and eventually running, up and down the 12 flights of stairs in my apartment building. Standing on top of that mountain watching the sun rise, holding Tony's hand, was a poignant moment for me." She reports that her lesions have healed and are no longer visible on an MRI scan. She considers herself recovered from MS.

By 2006, seven years after his own diagnosis, George Jelinek was also symptom-free and, over the next three years, he gradually weaned himself off his medication. But the permission he'd given himself to start living a life of change brought seismic shifts in unexpected quarters. In 2001, he and Lee painfully separated. The pair don't speak but are close to their grown-up children: Sean is now an economist with the WA Treasury, Michael a musician, and Pia has just graduated from the University of Notre Dame Australia's School of Medicine in Fremantle.

Ten years ago, Jelinek married Dr Sandra Neate, a fellow emergency-medicine physician. Jelinek admits that even though he understood why Eva took her own life, her leaving him at 27 left him with a sense of abandonment. "In Sandra, I felt like I was coming home," he says. Neate says she was drawn to his warmth and thoughtfulness and a particular quality that, while excellent in a physician, is perhaps sublime in a spouse. "When you talk to him, he gives you his undivided attention," she says. "He'll always take what you're saying seriously." Incredulously, she adds, "He still answers every email he gets."

Piecing together a program for wellness from an expansive body of medical literature was one thing; Jelinek knew that to be taken seriously by his peers, he'd need to publish evidence that his formula, the *OMS Program*, worked. Already in contact with a lively community of followers worldwide, in 2012 he launched a survey of his own preventive medicine principles involving 2519 people with MS, aged 18 to 87, from 57 different countries.

The results make for compelling reading. Those participants with the healthiest diets – eating fish three or more times a week – have a hugely reduced risk (70 per cent) of becoming disabled. Those taking flaxseed oil have a 42 per cent lower risk of being disabled. The same group of daily flaxseed oil consumers experience

more than 60 per cent fewer relapses than those not taking it (regardless of fish intake), while the thrice-plus-weekly fish eaters have more than 50 per cent fewer relapses. "The study," says Jelinek, "moves the *OMS Program* beyond the realm of mere opinion."

Sadly, due to environmental factors such as sun avoidance, a diet high in saturated fat, omega-3 deficiency and lack of exercise, the world is seeing an increase in MS diagnoses – about three-quarters of them women. Still, the vast majority of them are told nothing by their treating neurologists about the relatively simple lifestyle changes they can make that could be more beneficial to their long-term prospects than the drug therapies they're usually prescribed.

In **2006**, a report published by the School of Public Health at Saint Louis University suggested that it takes an average of 17 years for original – or discovery – research to be integrated into mainstream medical practice. "The decision to adopt, accept and utilise an innovation is not an instantaneous act, but more often a *process*," wrote the authors.

Rebecca Hoover, an American blogger with MS, wrote in October 2013: "Seventeen years is a long time to wait for a physician or neurologist to catch up. When research shows that we can improve our health by improving our life styles and diets, we want to know now. It's no wonder so many of us are frustrated with our neurologists and other doctors."

Another blogger, an ardent "OMS-er", wrote that she was distraught one day after a routine visit to her neurologist. At the end of her consultation, she'd asked about Professor Jelinek and his regimen. She reasoned that with her neurologist being an MS specialist, he would surely know something about it.

But her doctor – whom she identified in her blog post only by his initials – threw her an irritated look before telling her that Professor Jelinek had failed to meet the diagnostic criteria, known as the McDonald criteria, for MS. He'd had no further relapses of the disease, her specialist was suggesting, because he'd never actually had it in the first place.

Jelinek immediately weighed in online to reassure her that he had received

(continued on page 6)

(continued from page 5)

a clinically definite diagnosis of MS after a second MRI in 1999 confirmed a new lesion. "A friend of mine once warned me that if I stayed well long enough, people would say I didn't have the disease," he wrote.

He remembers the incident: "While surprised at this apparent questioning of the diagnosis, in many respects I found it understandable. I'm sure for a clinician used to seeing people with MS routinely deteriorate over time, it can be difficult to rationalise the situation of someone getting better and staying well as it's outside the usual paradigm." (The neurologist in question declined to be interviewed for this story.)

Dr Matthew Miles, the CEO of MS Australia Research, is an imposing-looking man in a dark suit. When I meet him in his North Sydney headquarters, he is polite, but assiduously noncommittal. "Diet and lifestyle factors in MS are nothing new," he says carefully, "but there is increasing evidence that a high-fat diet is less conducive to a good outcome.

"How neurologists behave in the future is dependent on the research. We still need that evidence base with diet. The thing about diet is that it's hard to show cause and effect. You can say, 'I'm on this diet and I'm doing better,' but *what part* of the diet is causing you to feel better? If you took that something away, could you prove that the beneficial effect also goes away?

"We're currently doing the world's largest clinical vitamin D trial to find out whether it can be used as a preventive measure," continues Miles. "We should have some results by the end of 2018."

For Dr Michelle O'Donoghue, an assistant professor of medicine at Harvard Medical School who was diagnosed with MS at 33, it's precisely Jelinek's "commitment to using an

evidence-based approach" that resonates for her. She has been following a plant-based diet with fish for more than six years now and says, "I've never felt better. Since making the dietary changes I've had no evidence of new lesions on MRI scans and I've been very fortunate to have never experienced a relapse."

When O'Donoghue was diagnosed, her MRI scan showed between 25 and 30 brain lesions. "The weight of the data," she adds, "strongly supports making the lifestyle and dietary changes he recommends."

In 2014, the morning after his 60th birthday, Jelinek woke up, looked at his phone and saw that someone had given him \$1 million to set up his own research centre at a place of his choosing. He didn't think twice. The result is the Neuroepidemiology Unit in the Melbourne School of Population and Global Health, which he opened last year. The unit's mission is to expand the evidence base around a preventive medicine approach to managing MS.

Jelinek's benefactor was none other than Linda Bloom, who is now married to her Kinabalu-scaling boyfriend, Tony. The pair live in London with their two young children. "OMS helped me regain my life," she says simply, her large dark eyes glowing with conviction. The unit is now entirely philanthropically funded and Jelinek is revelling in the independence.

Pia Jelinek, 24, with an A-list smile and the charisma to match, is now interning at her dad's old hospital, "Charlie's", in Perth. In October, she flew with him to the US, where he presented OMS workshops in LA, Boston and New York. Sharing a stage with him, she spoke to audiences about her unique experience growing up in the shadow of not one, but two MS diagnoses. "I'm incredibly predisposed [to develop MS]," she says,

"but if I ever were to be diagnosed, it wouldn't be the worst thing in the world. I know I'd be able to manage it. Besides, I'm an 85 per cent 'OMS-er' already."

She tells me about a patient she saw recently: a 70-year-old woman with MS who was recuperating from a knee replacement. Apart from her recent surgery, she was clearly doing very well. Pia asked her what she did to manage her illness. "Well," she said matter-of-factly, "I avoid saturated fats and I take vitamin D and flaxseed oil every day. Oh, and I do tai chi, too." I wrote down the name of Dad's OMS website and gave it to her. She looked at it and said, "Oh, I know all about OMS! George Jelinek? Why, he's done so much for me!" When I told her he was my dad, she started to cry. It's really nice seeing people like that."

WHAT IS MS?

More than 23,000 Australians are currently living with this disease of the central nervous system. It's caused when the body's immune system malfunctions and starts to attack the fatty coating, or myelin, that protects nerve fibres, interrupting messages between brain and body. This creates a host of symptoms, including loss of vision and mobility, cognitive decline and intense fatigue.

THERE ARE FOUR TYPES OF MS

Relapsing-remitting (RRMS), where attacks, or relapses, are followed by periods of recovery, partial or total; Secondary Progressive (SPMS), a worsening of RRMS so that it becomes a steady, continuous slide towards disability; Primary Progressive (PPMS), a steady course of decline from the outset; and Progressive-relapsing (PRMS), where a continuous decline is punctuated by severe flare-ups. Traditionally, there has been no cure. The chances of a child with a parent who has MS getting the disease can be as high as one in five.

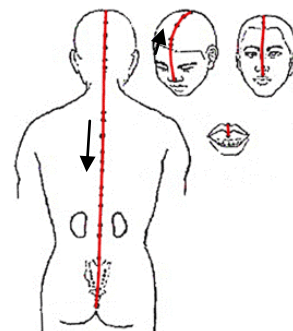
FROM: Sydney Morning Herald—Good Weekend. 21 January 2017

Body Code/Emotion Code meeting

On Saturday 11 February 13 CISS members attended a meeting where Body Code/Emotion Code practitioner Fiona Maile, from Perth, showed us how it is done. She showed with two volunteers how this technique uses muscle testing to identify trapped emotions that are causing ill-health, including cancer, and how the trapped emotions identified are then released using a magnet moved repeatedly along the body's Governing Meridian (see diagram).

For those interested in trying this technique contact the CISS Office. A good introduction to the DIY Emotion Code version of the technique is given in Bradley Nelson's book *The Emotion Code* (~\$24 from the UK Book Depository, incl postage).

After this Group Session Don Benjamin showed the DVD "Stress—Portrait of a Killer" (available from the library) and summarised the evidence linking chronic stress and cancer.



CISS STORIES-Nick Di Camillo

My experience with the "C" word started with my Dear wife discovering a lump on my left Breast. It was one morning in September 1998 while we had a quiet lie-in discussing everyday matters or maybe nothing at all.

As men rarely inspect their breasts for lumps this was a fortunate discovery and we agreed that I should monitor it for growth or any changes which I did.

About a month later I felt that the lump had grown even though minutely and that it was fairly hard when squeezed between two fingers.

I decided with some prodding, that it was a good idea to visit my GP and after a visit to him and getting referrals for Ultrasound and a fine needle aspiration (FNA), was told by my GP that breast cancer (BC) in men is rare and he felt all would be good.

In the meantime we had booked a trip to the Gold Coast for November-December of that year and so my view was that I was going to go and enjoy my Holiday without confirmation either way as to the malignant or benign status of the lump in my breast.

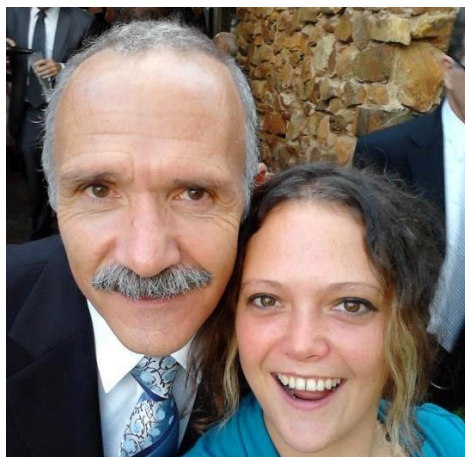
After a glorious holiday on the Gold Coast I returned and made the visit to the Radiology Clinic. The Consulting Radiologist felt he would only do a FNA after an ultrasound and then a mammogram. His reason was that the FNA would affect the quality of the pictures from the ultrasound.

Sure enough when the results came through and while visiting my GP to get the results, the Pathology report said that the lump was, according to the FNA result, "highly suspicious for malignancy."

My GP proceeded to refer me to a General Surgeon whom I saw at the Mercy Hospital in Maylands Western Australia.

I made the appointment and when arriving at the consulting room was asked by the receptionist if I had private hospital cover. Isn't it amazing that we get asked about our hospital cover status so quickly when visiting private surgeons. While they will say that it is to protect your hip pocket, I am convinced that all surgeons must feel quite relieved and on a "Licence to Operate" when you confirm that you have private cover.

My Surgeon recommended that the



Nick Di Camillo, with niece

lump be removed and a frozen section be performed as he was quite sure that the lump was cancerous and, if after inspection it was found to be cancerous, he wanted permission to perform a complete Mastectomy of my left breast. Also he would do an axillary node dissection which no doubt would have left me with edema and heaven knows what else. All this topped up with a good dose of radiation and chemotherapy. His opinion was based on the FNA report which really was not conclusive at all.

He even kindly suggested that he had an opening the following week and that his Secretary could book me in there and then. I thanked him and, as my wife and I were too stunned to really make decisions at the time, said that we would call him in the next day or two.

After we arrived at home and being barely able to eat we weighed up our options: do we go with the eager surgeon or wait a little longer and get a clearer picture of the road we had to travel.

We opted to wait and try for a second opinion and to treat "the condition" as I called it with some herbal remedies as my wife was a Remedial Therapist and we had used herbal remedies for some years.

Within the next two days we had a call from the surgeon's secretary who asked if we had made a decision as she could book us in with that phone call. I informed her that my decision was to wait and explore our options and to thank the surgeon for his advice and that we would not be hastily travelling down the route he had offered to us. I said that if after investigation I found that it was best to return to him for the surgery he had prescribed, then I would call and dis-

cuss it with him.

Well obviously the new Rolls Royce was on order and the hospital theatre empty where he had his room as, the following day, I had a call from the Eager Surgeon himself. He proceeded to explain that I was making a big mistake in not immediately having the recommended surgery as he felt quite strongly that I might even have a Melanoma (This all from the inconclusive FNA and his physical inspection). Whew what pressure.

Well I refused to help him get his Rolls Royce and declined his offer once again and we ended the conversation. I can truly say that medical practitioners must not even consider the pressure and anxiety that they can bring to people with such behaviour, even if it is well intentioned.

At this time my sister happened to mention a GP that she had known for years and that had experienced cancer himself. A visit to him proved to be the best thing for me when he proceeded to recommend how he would proceed with my situation. His advice was that he saw no problem with a lumpectomy with no axillary lymph node dissection and to assess further treatment after the lumpectomy. This release from the pressure to immediately spring into action was like a huge weight being lifted off my chest. Suddenly the dark tunnel had a light at the end of it.

In December of 1998 I had my lumpectomy performed by a well known female breast surgeon who performed the operation under a local anaesthetic. A couple of days later after the tumour had been assayed by the pathologist we were invited back to the breast surgeon's to be told that the final report was "Infiltrating Ductal Carcinoma Grade 3". She advised a dose of radiation and chemotherapy as being the norm. I declined the norm and said that I would deal with the cancer with nutrition and herbal products which left her speechless. However she said "if that's your wish then it's your right."

I need to mention that at this stage the important hormone receptor immunohistochemistry report was not to hand; but after the surgeon received it she should have passed the results on to me but FAILED to do so. (The report dated 18/12/98 was made known to me by my later-on oncologist who had

(continued next page)

shared rooms with the surgeon.)

My GP had looked at the available reports and had felt that my prognosis was good and supported my course of action.

Anyway I got on with life and herbal preparations and a mostly vegetarian diet with exercise etc. and about a year later went on a lovely trip with the family. This was in November to early December of 1999 to New Zealand.

Traveling around NZ which is not exactly hot at that time of the year I contracted a cold which I still had when I returned to Australia and on a scheduled visit to the GP mentioned earlier, for a regular ultrasound referral, he asked if anything else was of concern.

My wife jumped in and said she was concerned about the cold that had lasted by then about three weeks and so an X-ray was arranged. Well after having the X-ray on 20/01/2000 and on inspection of the photo, I was informed that it was advisable to have a CT scan as there were shadows on my lungs. My GP had consented to this and off we dashed to another centre for an urgent CT scan.

We were able to wait for the results and then were to take these to the GP. The results confirmed the X-ray and the official interpretation was:

1. "Multiple irregularly marginated opacities scattered through both lung fields, with extension towards the pleural surfaces in the upper zones which are suspicious for lung metastases. Widening of and increased density of the right superior mediastinum, suspicious for lymphadenopathy."
2. "Superior mediastinal lymphadenopathy which is also likely to be metastatic."

The GP said that he needed us to move on to specialist help and referred me to an oncologist whom I proceeded to visit about March 2000 and who on looking at the CT photos pronounced "I am telling you that this metastasizing breast cancer", in response to my wife's question as to whether the opacities, lesions etc. may have been scarring from who knows why and when.

I asked her what her treatment recommendation was and did she recommend radiation, chemotherapy etc. She said no, that my cancer would be treated the same as female BC and that was with Tamoxifen.

It's interesting that the other surgeons all would have treated me with chemo and radiation.

She also said that she had the hormone receptor immunohistochemistry report and was very annoyed that her previous room sharer i.e. my breast surgeon had not conveyed the results to me which were: Oestrogen receptor and Progesterone receptor positive. High content of ER protein and PGR protein, hence why she would use Tamoxifen.

We asked if she objected to me taking herbal supplements and her answer was that she did not care what I took as long as I did not take anything that would work against her treatment of Tamoxifen.

Especially I was not to have massive doses of Vitamin C. At this stage I was consuming oral Vit. C but was interested in this 'massive doses of Vit. C' idea. I did not know much about Intravenous Vitamin C but kept it filed away. Eventually a lecturer where my wife attended naturopathic classes suggested going to visit a Dr Bullen who conducted intravenous Vit. C clinics. That led me in July 2001 to Dr Ivy Bullen and her vitamin C days.

I commenced intravenous Vit. C in July 2001 at the rate of 30,000mg per visit every week after an initial consultation with Dr Ivy Bullen. She also recommended Mistletoe injections which I kept on injecting subcutaneously for seven years until 2008. I also self-medicated by adding dozens of other supplements such as Curcumin, I-3C (Indole 3 carbinol), Astragalus, St Marys Thistle, Green Tea capsules and heaps more. I used to rattle after I took the supplements, but did so religiously 3 times a day.

While I was having Intravenous Vit. C, I also had Tamoxifen but only took the Tamoxifen for two years from 2000 to 2002. I had researched and found that it's safe to take Tamoxifen for 2 years with a maximum of 5 years. The longer one takes the drug the greater the possibility of other cancers forming such as ovarian etc. Well I wasn't worried about my ovaries but did not want to risk another cancer forming, so I made sure that I only used 24 packets of Tamoxifen (as the packets lasted a month), over that two year period.

I kept visiting the oncologist who ordered one CT scan a year (after the initial one every six months) and she often remarked how well I was doing. I

did not tell her that I had stopped the Tamoxifen and I used to throw away her prescriptions so she was none the wiser.

On one visit to her in December of 2004 and after my not having taken Tamoxifen for two years she remarked to me how well the drug works on men and that she would continue to keep me on the Tamoxifen. My remark was Oh! Oh! and she straight away said "What? Haven't you been taking it?" My answer was "Not for two years".

Her statement was "Well whatever you are doing keep doing it as it is obviously working".

What else could she say as I was a medical miracle as, at the time of the first visit she had said to me after recommending Tamoxifen, "I can only offer you quality of life". Now suddenly the CT scans she saw in front of her looked like I was going to enjoy a long life even without Tamoxifen.

So here I was, confusing the oncologist and radiologists as the disease did not progress like they expected but in fact had remained stable for some years. The CT scans and X-rays should not have looked as they did in someone who was going to die a horrible death from cancer. The radiologists could not however offer acceptable explanations as to what the lesions etc. were that they were seeing on the films.

At this visit with the oncologist I offered to detail what I had taken and the protocols involved and send it to her if she was interested, to which she replied, "Yes I am interested, please do." She even said that she really did not need to see me again and we said our good byes.

Well its now 2017 and after turning 65 in December I am still here yelling and screaming and enjoying quantity as well as quality of life, which would not have been the case had I gone with the radiation and chemotherapy treatment. The evidence for intravenous Vitamin C is even stronger and more accepted today by many battling cancer and it is my experience that it, along with so many more nutritional supplements, are an effective and gentle way to overcome any cancer.

My journey with cancer has been interesting and a learning experience. It has taught me to never rush into any treatment or surgery without considering the consequences. It has taught me about maintaining my strong faith in God and

the benefits of a strong and positive outlook.

It has taught me how much support a loving wife was able to provide during those years in juicing vegetables every morning for me while attending Naturopathic College as well as running a household and still being there for our two girls who still lived at home. I owe her my eternal gratitude as she walked the journey with me without one complaint. I

am truly blessed to be as well as I am today and thank the creator of our wonderful bodies for the ability for it to heal itself as well as for making wonderful natural supplements for us to use in our fight against cancer and other diseases that befall all of us at some time or another.

I especially thank Dr Bullen (who

passed away two or three years ago) for her positive encouragement about the benefits of intravenous Vitamin C and making it available at very low cost to all that attended her clinic.

Nick Di Camillo
3rd January 2017
ciss@iinet.net.au

History of Immune Checkpoint Inhibition

by Ralph Moss, PhD

This month, for the second year in a row, the American Society of Clinical Oncology (ASCO) has chosen cancer immunotherapy as its breakthrough of the year. The emergence of immune checkpoint inhibitor drugs (such as Yervoy®, Opdivo® and Keytruda®) is undoubtedly a very important development in cancer treatment. But I thought readers would be interested in the history of the general idea of "de-blocking" the immune system.

The first researcher to postulate the existence of blocking factors in the blood serum of cancer patients was Ernst Freund, MD (1863-1946), of the University of Vienna. Working with his long-time associate, Gisa Kaminer (1883-1941), they anticipated many of the features of modern immune checkpoint inhibition. To me, they are among the unsung heroes of cancer immunology.

Freund and Kaminer suggested the existence of cancer-dissolving (or "carcinolytic") factors in normal blood serum. Serum from cancer patients, they said, contained "anti-carcinolytic" elements that protected cancer cells from some destructive element in normal serum. This distinction between normal and cancerous serum formed the basis of their "Freund-Kaminer reaction." Introduced in 1910, it constituted the first diagnostic test for cancer.

Freund and Kaminer believed that cancer could be diagnosed when a patient's serum blocked the destruction of cancer cells—in other words, through the presence of these anti-carcinolytic elements. It is hard to interpret these results in terms of modern science, but it is possible that Freund and Kaminer were actually measuring what we now call "PD-L1." This is a functional part of the linkage between the cancer cell and the immune T cell.

It is amazing to realize that Freund and Kaminer "attracted attention throughout the scientific world," according to a



Dr Lloyd J. Old & Helen Coley Nauts (c. 1980)

1924 article in Time magazine. The article continued:

"They have found in...persons with cancer a substance which, when added to the serum of normal persons, changes it to resemble the serum of persons with cancer. The normal serum loses its power to dissolve cancer cells...It is the belief of the Viennese investigators that...the chemical substances mentioned have the power of encouraging or preventing the growth of cancer."

Freund and Kaminer were of Jewish ancestry, and so, like thousands of others, had to flee for their lives after the Nazi Anschluss (annexation) of Austria in 1938. Like another Viennese professor, Sigmund Freud, MD, Freund and Kaminer found refuge in Great Britain. Kaminer died in 1941 and Freund died five years later. By then the British Medical Bulletin referred to their once-famous test as a "half-forgotten chapter of cancer research." By the 1950s it was completely forgotten, one of those scientific discoveries that did not survive the turmoil of World War II.

Enter the Hellströms

Then, in the late 1960s the husband-and-wife team of Karl Erik and Ingegerd Hellström gave new life to the study of blocking factors. The Hellströms came to the University of Washington from the famed Karolin-

ska Institute. In Seattle, for the next 40 years, they pursued blocking factors in the blood of cancer patients, as well as many other aspects of cancer immunotherapy.

The Hellströms' starting point was similar to Freund's, in that they found that adding "tumor fluids" from cancer patients' blood to immune cells would "specifically block the ability of human lymphocytes to kill ... tumor cells." (Sjorgen 1971).

When these still-undefined factors were removed, immune cells were once again able to attack cancer cells. The Hellströms wrote:

"Sera from mice carrying progressively growing sarcomas...can block the cytotoxic effect of lymphocytes immune to the tumor-specific antigens of the respective neoplasms [i.e., cancers]. The blocking effect can be specifically removed by absorbing sera with the respective types of tumor cells." (Ibid.)

A search to define these blocking factor began among immunologists. A major problem was that scientists could not reach a consensus over the exact nature of this blocking process. To quote Prasanta K. Ray of the Medical College of Pennsylvania and Hospital in 1981:

"It is not clearly understood how a tumor can grow in an individual despite the fact that the host may have anti-tumor immunity" (Ray 1981).

Prof. Fernando S. Salinas of British Columbia concurred:

"The nature of these blocking factors still remains unclear" (Serrou 1981).

In the past few decades, though, several important discoveries have shown how cancer can block the immune system. The most important of these is the theory of immune checkpoint blockade.

Unconventional Practitioners

This was also the point at which conventional oncology and CAM converged. Several unconventional practitioners, such as Lawrence Burton,

PhD, founder of the Immuno-Augmentative (IAT) treatment center in Freeport, the Bahamas; Valentin I. Govallo, MD, of Moscow, Russia; and M. Rigdon Lentz, MD, an American oncologist who still practices in Prien, Germany, all postulated various methods for "de-blocking" the immune system of cancer patients.

A new era began when James P. Allison, PhD, now head of immunotherapy at the University of Texas MD Anderson Cancer Center, Houston, showed that directing monoclonal antibodies ("guided missiles") against a so-called checkpoint protein, CTLA-4, helped mice fend off tumours. In a now classic paper, he and his colleagues wrote:

"It has recently become apparent that CTLA-4...is a negative regulator of T cell activation....Antibodies to CTLA-4 resulted in the rejection of tumors, including pre-established tumors These results suggest that blockade of the inhibitory effects of CTLA-4 can allow for, and potentiate, effective immune responses against tumor cells." (Leach 1996).

In other words, if you could eliminate the factors that are blocking the immune system, you might eliminate the cancer as well. This was the beginning of the development of "immune checkpoint inhibitors" (or blockade), the most important development in cancer immunotherapy in many years.

The first drug that directly targeted CTLA-4 was approved 15 years later, ipilimumab (Yervoy®). The U.S. Food and Drug Administration subsequently approved other checkpoint drugs, including nivolumab (Opdivo®) and pembrolizumab (Keytruda®), both of which target a related protein, PD-1. In 2015, Allison won the Lasker-DeBakey Clinical Medical Research Award. This is frequently a precursor

to the Nobel Prize in Medicine or Physiology, for which he allegedly has been short-listed.

Line of Descent

Almost 50 years ago, Helen Coley Nauts, the dynamic founder of the Cancer Research Institute (CRI), New York, published a series of 17 detailed monographs on the beneficial effects of acute concurrent infection, inflammation, fever or immunotherapy on a variety of cancers. The series included almost 1,000 cases of advanced cancer that had been successfully treated by her father, the great William B. Coley, MD, using a combination of killed microbes called Coley's toxins, Coley's fluid or mixed bacterial vaccine (MBV). I keep the set that she gave me almost 40 years ago close at hand and consult it frequently.

But, at the time, Mrs Nauts' valiant attempts to defend and revive her father's epochal work was almost entirely ignored or ridiculed. I remember seeing her monographs on a shelf of Cornell University Medical College, literally gathering dust, unread and unappreciated. At the time, almost the only scientist who took her work seriously was Lloyd J Old, MD, the young vice president of Sloan-Kettering Institute, who became the first scientific director of the CRI.

Fast-forward 40 years, and the present-day director of the Cancer Research Institute's Scientific Advisory Council is none other than James Allison, who, as I said, developed the first immune checkpoint inhibitor. So, through these individuals--Nauts, Old and Allison--there is direct line of descent from William B. Coley's toxins to the present generation of immune-checkpoint inhibitors. But we must also pay homage to the unsung heroes of this tale--Freund, Kaminer, the

Hellströms, Burton and Lentz. Without them, I doubt if this field would ever have come to its present-day position of eminence.

References

- Anonymous. Medicine: Chemistry of Cancer. Time, Jan. 28, 1924.
- British Council Medical Department. Lactation: Function and Product, British Medical Bulletin. London: Churchill Livingstone, 1947, p. 259.
- Freund E and Kaminer G. Ueber die Beziehungen zwischen Tumorzellen und Blutserum. Biochem Ztschr. 1910;**26**:312-324.
- Govallo VI. Immunology of Pregnancy and Cancer. Moscow: Nova Publishers, 2003.
- Leach, DR, Krummel MF, Allison JP. Enhancement of antitumor immunity by CTLA-2 blockade. Science 1996;**271**:1734-1736.
- Lentz, MR. The Role of Therapeutic Apheresis in the Treatment of Cancer: A Review. Therapeutic Apheresis: Official Journal of the International Society for Apheresis and the Japanese Society for Apheresis 3, (February) 1999; **1**: 40-49.
- Paulson, Tom. 40 years ago, this Swedish couple pioneered cancer immunology. Seattle PI, (Feb. 23) 2006; I can find no references to Freund and Kaminer in their writings.
- Ray, P. K., and S. Raychaudhuri. Low-Dose Cyclophosphamide Inhibition of Transplantable Fibrosarcoma Growth by Augmentation of the Host Immune Response. Journal of the National Cancer Institute 67, (December)1981: **6** :1341-45.
- Bernard Serrou, Claude Rosenfeld. Immune Complexes and Plasma Exchanges in Cancer Patients. Elsevier/North-Holland Biomedical Press, (Jan 1) 1981: p. 253.
- Sjögren, H. O., Hellström I., Bansal S. C. and Hellström K. E. Suggestive Evidence That The 'blocking Antibodies' of Tumor-Bearing Individuals May Be Antigen-Antibody Complexes. Proceedings of the National Academy of Sciences of the United States of America 68, (June) 1971; **6**: 1372-75.
- Ralph Moss, 15 February 2017
www.ralphmossblog.com/2017/02/history-of-immune-checkpoint-inhibition.html

Immunotherapy for Cancer — This Lauded Breakthrough Is Far More Dangerous Than Advertised, by Dr Mercola

Immunotherapy drugs are considered the latest and greatest breakthrough in conventional cancer treatment. Chimeric antigen receptor technology (CAR-T) has raised a great deal of hope, and an equal measure of concern.

CAR-T involves genetically reengineering a patient's immune cells to target tumor-associated antigens, thereby destroying the malignant cells.

Alas, while these therapies appear to be quite effective at attacking and destroying malignant cells, they can also take a toll on healthy tissues and organs, leaving many patients struggling for their lives, albeit for an entirely different reason.

There's also another important issue at stake here. CAR-T cell therapies such as the one developed by Novartis (see below) have been granted

PRIME¹ (Priority Medicine) status by the European Medicines Agency (EMA). PRIME is similar to the Breakthrough Therapies program² offered by the U.S. Food and Drug Administration (FDA). Both of these priority medicine programs aim to speed up approval of novel drugs in order to bring hope to patients for whom there is little or no hope.

While this is admirable, it's also a slip-

pery slope that can end up affecting people with non-lethal diseases as well — people who are NOT quite as keen on playing Russian roulette with their health for a chance of survival.

Immunotherapy Drug Trials Show Severe Side Effects Are Common

A study³ published in 2010 found that ipilimumab — an immunotherapy drug that blocks cytotoxic T-lymphocyte antigen-4, used against advanced melanoma — caused severe side effects in nearly 20 percent of patients.

Another study⁴ published in 2015 found adverse events in 24 percent of patients receiving ipilimumab, and when used in combination with nivolumab, another immunotherapy drug, severe adverse reactions occurred more than half the time.

Despite that, the study, funded by Bristol-Myers Squibb, concluded that the combination therapy “had an acceptable safety profile.”

Most recently, a study⁵ published this summer found 30 percent of patients receiving either pembrolizumab or nivolumab suffered “interesting, rare or unexpected side effects” from the treatment.

No less than 242 different side effects were noted in all, including skin, gastrointestinal, liver, endocrine and renal system effects, diabetes mellitus and pancreatitis. One-quarter of these reactions were severe or life-threatening and required hospitalization.

Novartis is now seeking approval for CTL109, a drug shown to be effective against pediatric B-cell acute lymphoblastic leukemia.⁶ In its phase 2 study, 82 percent of pediatric and young adult patients experienced complete remission. However, for many the victory was short-lived. Six months later, 40 percent of them had relapsed. Some of the side effects were also severe. Fifteen percent of patients experienced grade 3 neurological and psychiatric events, including encephalopathy (abnormal brain function) and delirium.

Adult Leukemia Trial Put on Hold After Additional Deaths

Juno Therapeutics⁷ is working on an immunotherapy for adults with refractory B cell acute lymphoblastic leukemia. Its phase 2 trial was recently placed on hold for the second time this year following the death of two patients who developed cerebral edema,

just days after receiving their treatment.⁸ One of the patients was under the age of 30.

In July, the FDA ordered a clinical hold on the trial following the death of three patients. They too died from cerebral edema. As reported by CNN:⁹

“... [I]nvestigators pinpointed the likely culprit as the addition of fludarabine to the pre-conditioning regimen. Fludarabine is a chemotherapy drug used here as a one-time primer for treatment ... in an effort to increase the effectiveness of the experimental therapy.

In this particular course of treatment, pre-conditioning consists of a heavy dose of chemotherapy to kill off existing cancer cells in order to give the new cancer-killing T-cells room to grow. It's like hitting a reset button to restart the immune system. But an unforeseen interaction between fludarabine and genetically modified JCAR015 cells proved to be lethal.”

The trial was given the green light to resume in August — this time without the use of fludarabine. Still, two patients are dead from the same exact problem as the initial three, suggesting the chemotherapy drug wasn't the problem after all.

Brad Loncar, founder of a cancer immunotherapy fund told STAT News¹⁰ that Juno was “going way too fast. It's just terrible. They've killed a couple of people, and it seems like, in part, it's because of the rush to judgment.”

Out-of-Control Immune System Attacks Healthy Organs

The New York Times (NYT) recently published a very comprehensive article well worth the read that details the struggles of Chuck Peal, who took part in a melanoma study at Yale. He received the ipilimumab with nivolumab combination.

Seven weeks later, he developed acute-onset diabetes — a brand new form of type 1 diabetes, to be exact, associated with these kinds of immune-altering drugs. Type 1 diabetes typically strikes during childhood, but these drug-induced cases involve older patients who very suddenly lose all of their insulin production. As reported in the article:¹¹

“He slipped in and out of consciousness, his blood pressure plummeted, his potassium levels soared and his blood sugar spiked to 10 times the normal level ... [He] spent 24 days in

the hospital... First his pancreas failed, then his bowels inflamed and his kidneys became dysfunctional, and 'to top it off, he has a fever of 103 for which we can't find a source,' Dr. [Harriet] Kluger said in an interview during the crisis ...

Peal's body was attacking itself, a severe reaction by his immune system that was a side effect of a seemingly miraculous cancer treatment aimed at saving his life ... [A]s their use grows, doctors are finding that they pose serious risks that stem from the very thing that makes them effective.

An unleashed immune system can attack healthy, vital organs: notably the bowel, the liver and the lungs, but also the kidneys, the adrenal and pituitary glands, the pancreas and, in rare cases, the heart.

Doctors at Yale believe immunotherapy is causing a new type of acute-onset diabetes, with at least 17 cases there so far, Mr. Peal's among them.”

Playing With Fire

According to Dr. John Timmerman, an oncologist and immunotherapy researcher at the University of California, the use of immunotherapies is a dangerous game. “We're playing with fire,” he told the NYT, shortly after losing a female patient to the treatment's after-effects.

Weeks after the drug sent her cancer into remission, she suddenly developed cold and flu-like symptoms that quickly killed her. The real cause of death? A massive, out-of-control inflammatory response mounted by her altered immune system. As reported in the featured article:¹²

“With lives to be saved and billions of dollars to be made — \$250,000 or more is the list price for a year of some regimens — not enough research has been done into the risks of the new therapies, said William Murphy, [Ph.D.] a professor of dermatology at the University of California, Davis, who reviews immunotherapy-related grants for the government.

It is ‘a massively understudied area,’ Murphy said, adding: ‘The No. 1 priority is anti-tumor effects. Everything else, however severe, is considered the price worth paying.’”

Indeed, according to Murphy, only three of the 500 research proposals he reviewed were focused on toxicity.

(continued on page 3)

What's Available from the CISS Office?

Branches of CISS

NSW

CISS CENTRAL COAST

The Central Coast Branch holds a general meeting on the third Monday of each month at the Arts & Crafts Centre, Henry Kendall Gardens, Bellbird Drive (off Maidens Brush Rd, Wyoming at 7pm with a guest speaker and sharing of information and common experiences. An excellent library is available to members. All are welcome. For further information contact Mary Sponberg-Macready on (02) 4322 8767.

CANCER SUPPORT GROUPS

NSW

ACTIVE WOMEN TOUCHED BY CANCER & CELEBRATING LIFE

Meets at Balgowlah RSL, Ethel St, Seaforth on 2nd Tuesday of the Month at 7pm. \$5 donation. Guest speakers. Contact Robin 9938 6128 or Kate 8902 0196

BLUE MOUNTAINS CANCER HELP INC, KATOOMBA

Support groups and complementary therapies. Groups include the Gawler "Living Well" 12 week program at Katoomba and Springwood, and a Breast Cancer group. Regular support groups held twice a month. A not-for-profit charity supported by our op shops. Phone 4782 4866 www.cancerhelp.net.au.

CANDLES CANCER SUPPORT GROUP

Meets Fortnightly [Thursdays] 10-noon Kanwal Community Hall, Pearce Rd Kanwal [Central Coast] Provides information, support, empathy and understanding. Phone/email contact available if unable to attend meetings. Open to all types of cancers patients, male and female. Survivors and carers all welcome. Contact: 4393-5017 for details.

CANHELP CANCER SUPPORT GROUP

Based on the Ian Gawler approach. Meets 1st & 3rd Tuesday each month from 6.00-8.00pm at Level 3, 280 Pitt St. Enjoy meditation, sharing and support. Ring Sue Saxelby 0408 442 030 or just turn up.

HILLVIEW COMMUNITY SUPPORT GROUP

Meets each Tuesday 1.30-3.30pm at 1334 Pacific Highway Turrumurra. Includes a meditation. No charge. Phone 9449 9144 and ask for Patricia Krolik.

KEMPSEY CANCER SUPPORT GROUP

This group for cancer patients and their carers meets on the 1st and 3rd Wednesday of each month from 10 - noon at the Community Health Building. Contact Penny Snowden 6562-6066.

NAMBUCCA VALLEY SUPPORT GROUP

Meets every Wednesday, Agnes Grant Centre, Macksville & District Hospital, 11 am – 1 pm. Phone 6568 2677.

CHAMPION Juicer - \$575 (\$615 non-members)

OSCAR Juicer - \$485

DVD: CISS 2007 Seminar : Cancer & Hope

Enema Kits: \$12.00

\$29.50 plus \$5 postage

Hydrazine Sulphate: 250ml - \$15; 375 ml - \$22.50; 500 ml - \$30 + postage

Vitamin C: Powder - 450gms \$17 for the most common combination of Ascorbic

Acid 200gms and Sodium Ascorbate. 250gms - **30% off**—past best before date

Water Purifier: Reverse Osmosis - \$495. Other models avail.

Xylitol: (sugar substitute) - 450gms - \$7.00

Prices are subject to change. Items can be posted to you. There is a \$10.50 postage/packing fee for standard articles, \$12-\$16 for country and interstate, \$16 Express Post. CISS Handbooks \$13.50, \$15 including postage.

NEWCASTLE CANCER SUPPORT GROUP

For information contact Make Today Count, 44 Dudley Road, Charlestown, NSW 2290. Phone 4943 8462.

PARKES CANCER SUPPORT GROUP

Meets every 3rd Monday of the month at the Education Centre, Parkes District Hospital at 1.30pm. For further information contact Margaret Green, 6864-5123 or Mary McPhee, 6862-3814.

QUEST FOR LIFE FOUNDATION

Based on 30 years of delivering exceptional retreat experiences for people living with cancer, our 5 day residential retreats deliver the latest research on health, healing and neuroscience. Contact 02 4883 6599 or visit www.questforlife.com.au

SUTHERLAND SHIRE CANCER SUPPORT GROUP

Meets every Tuesday morning from 10.30-12.30 at the Parish Centre of the Catholic Church, 50 Kiora Road, Miranda. For further information contact Deborah Harrison, 9523 5200.

SYDNEY ADVENTIST HOSPITAL CANCER SUPPORT CENTRE

Meets each Wednesday 10-12 noon at Jacaranda Lodge, 185 Fox Valley Rd, Wahroonga. A discussion group for patients and carers of any cancer type. Also special support groups for different cancer types and for carers. Contact Nerolie on 9487 9061.

VICTORIA

CANCER NATURAL THERAPY FOUNDATION

Support group meets on Tuesday nights at 7pm at 531 Elizabeth Dr, Sunbury, Victoria 3429. Meeting includes discussion, relaxation therapy and Reiki Healing. Certified organic produce available these nights. The Foundation operates a resource library, workshops and guest speaker program. Personal Counselling available. Contact Sandra Givca Maqueda (03) 9740 9921; mobile 0411 100 947.

GAWLER FOUNDATION

Learn how to create wellness in the face of cancer at our 5-day and 10-day Cancer Retreats in Victoria's beautiful Yarra Valley. Call 1300 651 211 or visit www.gawler.org to learn more.

QUEENSLAND

FRUITARIAN RAW FOOD NETWORK

Write to PO Box 293 Trinity Beach Qld 4879.

QUALITY OF LIFE CANCER SUPPORT GROUP

Meets on the North Side of Brisbane. For details phone Alan on 3263 8390 or Michelle on 3269 9687.

WESTERN AUSTRALIA

CANCER SUPPORT ASSOCIATION of WA

Cancer Wellness Centre, 80 Railway St Cottesloe WA 6011. Counselling hours: Tues-Thurs. Phone (08) 9384 3544. The CSAWA Inc is a non profit organisation with the primary objective to provide support services, information and self-help activities in a safe and caring environment for people affected by cancer, to enhance their emotional, physical, spiritual and mental well being. Emphasis on self-help & development, teaching life skills that enable individuals to better cope with the fear and uncertainty of a cancer diagnosis.

Website:

www.cancersupportwa.org.au

TASMANIA

KINGBOROUGH CANCER SUPPORT GROUP

Contact Tony Cope (03) 6227 7902 ah for further details.