



Welcome to the Brain Tumour Alliance Australia e-News

June 2019



ONE YEAR

This month we want to let you know what the e-News community has been reading over the 12 months since we launched in June 2018.

We've listed below, with one or two figures thrown in, the subjects of most interest to you. We hope it's been helpful to you on your journey - that it's provided a decent combination of information and inspiration. We have some more of that inspiration this month, with two more stories from people who cannot help but inspire with their resilience and strength of character.

In this edition: Exploring **better treatments** for brain tumours - the **Crowd Funding** for surgery debate - **Brain Injury Awareness Week** (highlighting brain tumours) - the **7 habits** of a highly **healthy brain** - **e-News in review** - **Patient Stories**

EDITOR'S NOTE: This is my final e-News. It's been a privilege to develop the e-News into what it is, informing, connecting and providing hope to the brain tumour community. For anyone wanting to stay in touch my website is [here](#).

Ka kite ano
Stephen Newman



Firstly... some News



EXPLOITING THE BRAIN TUMOUR ENVIRONMENT TO MAKE BETTER
TREATMENTS... 5 min read

Part of a series from *Cancer Research UK* exploring the major challenges holding back progress in the field of brain tumour research. This second instalment focuses on how understanding the environment in which a brain tumour grows could lead to better treatments.

[READ MORE](#)

Category: Medical Research



IF DOCTORS HAVE A DUTY OF CARE TO ALL, WHY CROWDFUND FOR SURGERY ... 5 min read

We're not afraid to address controversial issues and this one has once again initiated much public debate, hand wringing and mis-information. It's worthwhile including this article, from *Guardian* contributor and Oncologist Dr Ranjana Srivastava, to add some balance to the white noise surrounding a vexed issue. As we know, surgery is not the only component of the brain tumour journey.

[READ MORE](#)

Category: Treatment Options



BRAIN INJURY AWARENESS WEEK 19th-25th AUGUST 2019

Each year, Brain Injury Australia (BIA), during brain injury awareness week, focuses on a particular type of brain injury, this year it is brain tumours and will

focus on the stories of people with brain tumours. You can read more about the work of BIA on their website.

BRAIN INJURY AUSTRALIA WEBSITE

Category: Awareness

These are the 7 Habits of Highly Healthy Brains

THE 7 HABITS OF THE HIGHLY HEALTHY BRAIN

Brain health has always been an important component of the e-News, looking for ways to nurture our brain as well as heal it. Here is a useful PDF document for all of us, from Australian neuroscientist Dr Sarah McKay, talking about the habits of a healthy brain.

[READ MORE](#)

Category: Brain Health



A year in review... what we've been
reading



QUALITY OF LIFE

Quality of Life encompasses many things and we have published over 20 articles on the subject - including topics on brain health, exercise, stress, fatigue, memory and nutrition. Fatigue is a particular concern to us all, not only how we manage it but how we can make others aware of its impact on our lives - as such, articles on this subject alone made up 23% of QoL articles read. Overall, 25% of articles we ran pertain to our 'Quality of Life'.

Exercise is also a common theme, it's growing in importance and the link between exercise and brain health probably can't be understated - we are always on the lookout for information in that area that may help. The 'Walk Your Way to Better Brain Health' article was one of the most popular of all articles. We are always searching for ways in which we can nurture our brain and our body. Articles on these topics combined made up around 20% of QoL articles read.

Other articles on topics such as loneliness, anxiety and carer burnout were also widely read, making up 30% of all QoL articles read. We will continue to look for information in these areas that helps the community. We are particularly interested in resources that assist the carers among us - sometimes the carer gets neglected, it's often tougher being the carer than being the patient - the carer deserves to be cared for and acknowledged.

QUALITY OF LIFE ARTICLES

BRAIN HEALTH ARTICLES

EXERCISE ARTICLES

MENTAL WELLBEING ARTICLES

Category: Quality of Life



PATIENT/CARER STORIES

The reader response to the stories we've told has been overwhelming. As a society we need stories to sustain us, information is valuable but people telling stories that provide roadmaps for their community and their society is as old as civilisation itself - it helps us see through the maze - they tell us what sort of people we are - they inform but also inspire - we need these stories, it's medicine for the soul - we need

to celebrate the little victories, as tiny as they might be, we need to celebrate each others lives, regardless of outcomes. Stories of people provide colour, shade, nuance, things that mere facts, figures, research statistics and money can never do. Believe it or not, stories provide guideposts, they pick up the one who stumbles. The day we stop telling each others stories is the day we cease to be human.

Right alongside articles about Quality of Life, patient and carer stories have been the most read of all subjects we've covered - 10% of all articles combined. We won't single out any one story, they are all unique in their own way. These stories are not only the stories that the story-teller needs to tell but they are stories that we all need to hear. They are not sugar-coated tales of triumph, they are accounts of resilience amidst the confusion, they are courage mixed with fear. They don't turn a blind eye to human nature and they stand on their own hard won ground.

You don't have to be a wordsmith in order to tell your story - it oozes out of you.

PATIENT/CARER STORIES

Category: Patient/Carer Stories



COMPLEMENTARY THERAPIES

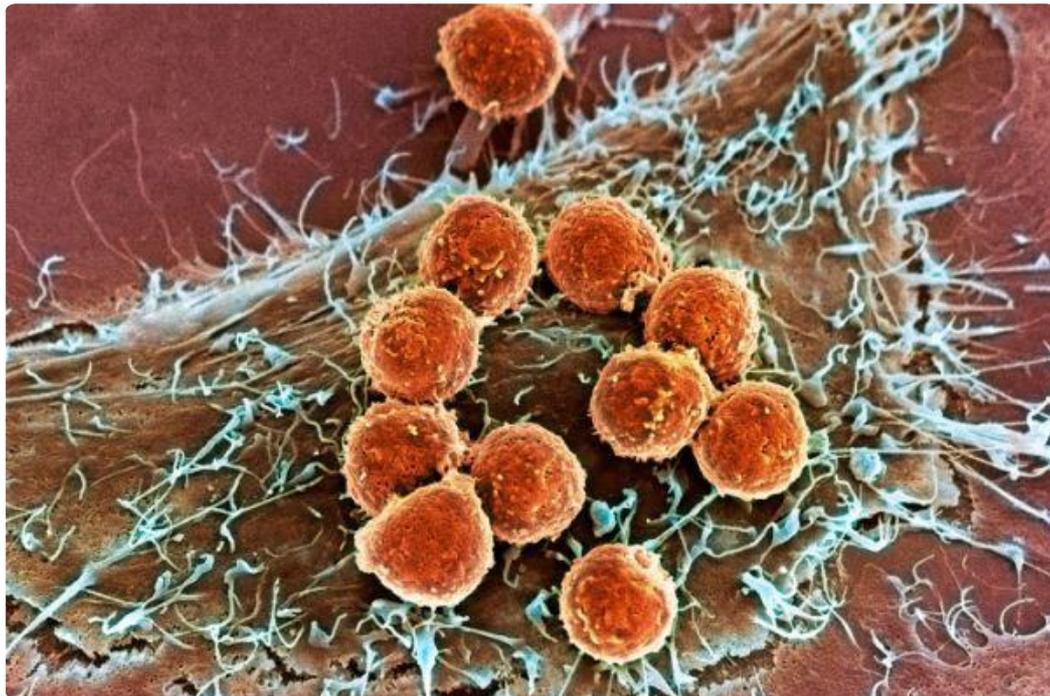
Let's face it, we all want to know if these things are any good. The big news story is of course, medical cannabis - there's no point shying away from it, the interest in its possible benefits, its side effects, its availability, its traps, is in the public domain. We will continue to keep an open mind about all alternative therapies, aware that for some people, these therapies are magic and for others less so.

Although we published only three articles about medical cannabis, the readership was strong, there is much interest in the subject - we will continue to make available any information that we think adds to the national conversation. We would also like to examine therapies other than medical cannabis - a complementary therapy means

just that, it complements our ongoing treatment, it doesn't replace it. The conversation continues.

COMPLEMENTARY THERAPIES ARTICLES

Category: Complementary Therapies



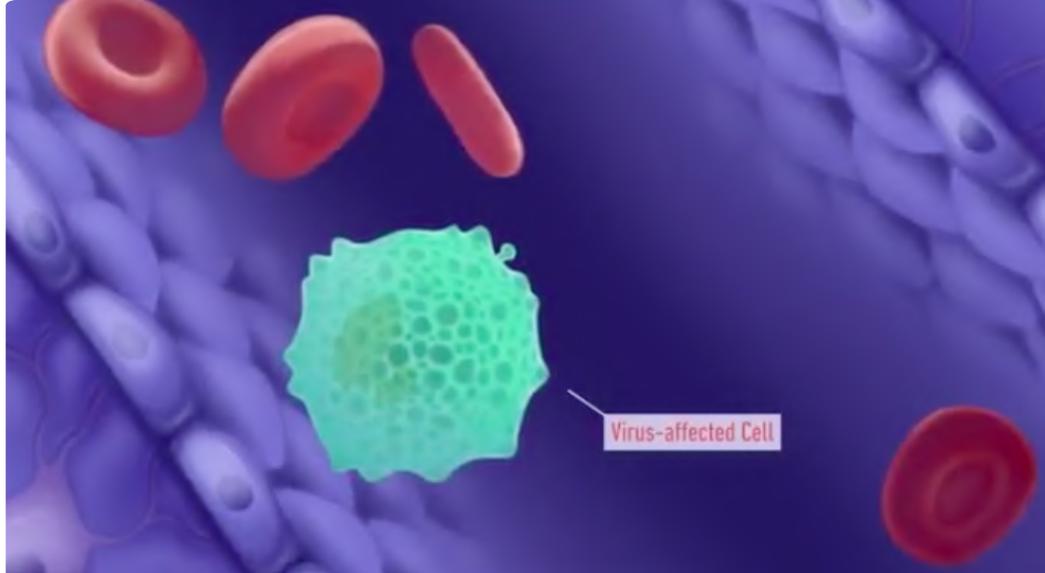
IMMUNOTHERAPY

We have published a dozen articles on the subject of Immunotherapy - sometimes described as the 'New Wave' of treatment, when in fact our immune system is fighting disease all the time, so in that respect it's not new at all. The trick for researchers is to find the key to unleashing our immune system and arming it to fight any disease that comes along.

Among the popular articles was the article in our June 2018 e-News about Dendritic Cell Therapy, the 'Immunotherapy Explained' Booklet from the Cancer Council and the '5 Lessons from our Immune System' article.

IMMUNOTHERAPY ARTICLES

Category: Immunotherapy



MEDICAL RESEARCH & CLINICAL TRIALS

Whilst Clinical Trials comes under the broad heading of Medical Research, it is its own particular discipline and of significant interest to the brain tumour community. Many of us search high and low to try and become part of a clinical trial, they aren't as easy as one might think to corral but equally, we want to know about the trials being run, the results that come from them, on behalf of our fellow travellers.

We all share a desire to see cures for this disease, we all want treatments that work - we advocate in our hearts on behalf of each other, we want to know that progress is being made. It's not always easy to find out exactly what that progress is but we will continue to ask the questions. We mine our great research organisations, big and small, for a scintilla of news, it's something we will continue to do.

We have published 23 medical research or clinical trials articles or papers. The most popular research articles were the Glioblastoma Vaccine research article; the idea that treatments for Parkinsons Disease may have some value to brain tumour patients; the CAR-T Cell Therapy work out of the Peter Mac Cancer Centre; the research paper out of Brainstorm and the Lifehouse Clinical Trial announcement.

[MEDICAL RESEARCH ARTICLES](#)

[CLINICAL TRIALS ARTICLES](#)

Category: Medical Research/Clinical Trials



LEGAL & FINANCIAL / SUPPORT PROJECTS / PAEDIATRIC CARE

Legal & financial issues are always going to play an important role in our journey, both before and after treatment. We've published 5 articles on this topic and covered the accessing of superannuation; offered case studies and published articles advocating on behalf of patients to make life easier on the hip pocket.

We've also published or promoted 12 different support projects, to remind us all that work is being done to provide the support we need. And whilst most subscribers are adults, there are many parents and guardians looking after children who are a part of our community - we will always keep a look out for our kids and publish anything that provides hope or guidance. Most of the articles we published around paediatric care pertained to breakthroughs and funding, which is always good news but we are aware also that more needs to be done, we'll keep doing our bit to promote anything that helps our children. These three topics made up 10% of all articles read.

LEGAL & FINANCIAL ARTICLES

PATIENT/CARER SUPPORT PROJECT ARTICLES

PAEDIATRIC CARE ARTICLES

Category: Legal & Financial; Support Projects; Paediatric Care



Amazing people with wonderful stories



THE STORY OF TRACEY & HER 36 HOUR SURGERY ... 7 min audio

Four years ago, Tracey Magno and her husband JP came to Canberra as young professionals. They lived active lives and loved to travel. Then, at the age of 31, Tracey was diagnosed with a brain tumour. Her road to diagnosis and life saving surgery is, in itself, a cautionary tale.

Her vision was deteriorating and after being told, initially, that her tumour was inoperable, received help from her friend, an optometrist, with the further assistance from an ophthalmologist colleague, who, after looking at her MRI scans, turned to his network of contacts within the community of neurosurgeons and made contact with Dr Andrew Davidson at Macquarie Neurosurgery in Sydney, who described the case as the most difficult he had ever encountered. Her surgery turned into multi-stage 36 hour surgery.

We have provided a link to a recent interview Tracey gave on the ABC Canberra Saturday Breakfast programme.

[LISTEN TO TRACEY'S STORY](#)

Category: Patient/Carer Stories



MICHAELA AND UDELLE THE LABRADOR... 5 min read

I have always loved volunteering, it does me good as well as doing some good for others. I used to help out at our son's school as a tutor, through the Smith Family, long before I discovered that I had a brain tumour - an Oligodendroglioma. English is my second language and so tutoring was also beneficial for me in that respect.

[READ MICHAELA'S STORY](#)

Category: Patient/Carer Stories



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