

BRAVEHEARTS

MAGAZINE

ISSUE 5



Brighter Futures for Childhood
Brain Tumour Survivors

CONTENTS

Featured survivor Ted (Edward) Reece	03	Achievements & Ambition	12
Knights Templar & Temple Church Written by Catherine Sutton	05	Puzzle Page Crossword Puzzle, Wordsearch, Spot The Difference	13
Braveheart's art & photos Synaesthete "We Three Kings"	07	Once in a lifetime Youssef Ghanem	15
Sophiyah Rayner - PART 1	09	Survivor Group	17
Save the Date 02.03.24	11	Submission Notice	18

EDITORS NOTE

Welcome readers to our special festive issue of Braveheart's. We have some exciting reads for you from our survivors and a bit of history on the Knights Templar & Temple Church, as well as a wordsearch for those of you who like a bit of a challenge.

Don't forget to save the date for the upcoming Conference on the **2nd March 2024**.

Elaine Perkins/Annabelle Higgins

- Contact us**
- Get involved**
- Join our survivor group**
- Write your story**

Get in touch:
Email: info@successcharity.org.uk

TED'S JOURNEY

I was diagnosed with an Astrocytoma Brain Tumour in December 2015 but my parents were told to tell me until after Christmas, so as not to spoil it for me. On 5th January 2016, my parents told me I would be going into hospital for Brain surgery. We got to the hospital early the next day and I was wheeled to surgery within 2 hours of arriving.

Hours later when I awoke in the recovery ward, I remember my vision being blurry and my hearing amplified and echoed. I had to stay in the hospital for 6 days while I recovered, and so when I went home, I was still all bandaged up.

About 2 weeks later discussions were started with my Consultant, Dr. Yen-Ching Chang, and it was decided that Proton Beam Therapy would be the best option for me. Things moved very quickly after that, and no less than a week later, I was on a flight headed for Oklahoma with my mum and dad.

After around 12 hours of travelling, we made it to Oklahoma Airport where we were met by Nicky, a member of the Procure family team. The next afternoon we were taken to the Procure centre to meet with my consultant for the duration of my treatment. He told me that they would need to make a mask to keep my head pinpoint still and said it would take 2 weeks to complete and make up.

The mask was made the next day and then we had 2 weeks to do whatever we wanted, so we all went to Disneyland Florida. On my return from Disneyland my treatment was started.

Over the next 2 and a bit months, I had an hour of Proton Beam Therapy every day, but this was not all doom and gloom. The treatment wasn't the only activity, as there were 6 other British families in similar situations, so after our treatment for the day was done, we would go out and do fun things together, like; Bowling, Arcades



or mini golf. There was only one day when I was really to ill and could not do something. In early April, my cousin and his wife, who were on a trip to New York, stopped by to visit us which was a wonderful surprise, and it meant a lot to me and my parents to have their support.

By the 18th April 2016, 2 month and a half months after starting my treatment (my course was extended) I was declared Cancer Free. We had another week in Oklahoma until we could fly home, so my parents and I focused on enjoying our remaining time there.

Then when it was time to return home, we packed up our life we'd made in Oklahoma and prepared for the move back to the UK. After arriving back in the UK, I was immediately put in contact with an Endocrinologist, as Proton Beam Therapy (PBT) was relatively new, and the doctors could not predict how I would be like after my treatment had ended.

I was lucky enough to be put under the care of Dr. Spoudeas, who now runs Success Charity. I had to have an MRI scan every 3 months and received heavy doses of steroids to help in my recovery. By August 2016, I remember starting to get a tight and swollen feeling in my throat, to the point that I could no longer swallow properly, so it was

decided in a heartbeat that I would need Brain Surgery which was scheduled the next day to investigate further. As it turns out, it was just scar tissue, so that was a relief. I did return to school briefly in June/July 2016, but then didn't go back again until mid- September due to my second surgery taking place.

A year passed since I had been diagnosed and treated but still had to see Doctors every week.

In 2017, I started Growth Hormone (GH) to help my body regulate its' growth and I was pretty much off the steroids all together by that time. I was still having MRI's every 3 months but seeing the doctors less often. I remained on GH until August 2020.

Since then, I took up Golf, which has been a major part of my life ever since, so much so, that in September 2023, I will be part of a golf team for my college. I will also be working with an agency called "Study and Play America", which will help me travel to the States once again, but this time, not for Cancer Treatment, but to play college golf.

Written by Ted (Edward) Reece



Knights Templar & Temple Church

Today's Carol Concert has been held at the Temple Church and here is a little background information on the Knights Templar and the Temple.

The Templars were a monastic religious order founded to protect pilgrims travelling to the Holy land and existed for about two centuries in the Middle Ages. They were founded in 1118 - 1119 in Jerusalem by Hugh de Payens and were granted the Aqsa Mosque on Temple Mount as their headquarters. The Mosque was called the Temple of Solomon as this is where the ruins were believed to be.

The Templars became known as the 'fellow soldiers of Christ and of the Temple of Solomon' and wore distinctive white mantles with a red cross.

People were initially suspicious of the Templars (who were skilled units in the crusades). They were reliant on donations to survive (their 'emblem' was of two knights riding one horse to represent their poverty) but this changed when they won the support of Bernard of Clairvaux, who led a group of churchmen to endorse the order on behalf of the church and the Templars became a favoured charity, receiving money and land. They developed an early form of banking and built a vast network across Europe and the Holy Land.

The Templars' first house (1140s) in London, was in what is now Holborn, about a mile from the present site of Temple church. The Templars sold the Holborn site in 1161 and the round church in the Templars' new temple was in use in 1163.

The current church recreates the shape of Constantine's memorial; a round church built over what was believed to be the grave of Christ in AD 325: The holy sepulchre, the centre of the centre of the world.

The Temple church was consecrated in 1185 by Patriarch of Jerusalem, Heraclius.

The round church may be the earliest Gothic building in England. The original chancel was much smaller than today's and the new (1240) one changed the balance between the two parts and shape of the church. Today's absence of decoration is modern. In the Middle Ages, there was paint on the walls and metallic paint on the ceiling.

The Pope abolished the order of the Templars in 1307 and King Edward took control of the Temple in London. This was given to the order of St John and the temple was rented to two colleges of lawyers, who came to be identified as the Inner and Middle Temples.

'For four hundred years the Temple Church has been in the care of Inner and Middle Temple, two of London's four legal societies, the Inns of Court'.

Significant events:

1666: Temple church narrowly escaped destruction in the great fire of London. The ground was scorched and buildings to the south and east were burnt down.

1680s: The inns refurbished their church in a classical style under the direction of Christopher Wren.

1683: commissioned a new organ

1840s: Whole church restored - restoration of the choir

1860s: The round's roof rebuilt as a steep cone to emulate the conical roof of the Holy Sepulchre in Jerusalem

1941: Bombed in the Blitz. If you would like to read up more on the Templars and the Temple Church, here are

By Catherine Sutton



www.templechurch.com/history



www.en.wikipedia.org/wiki/Knights_Templar



www.templechurch.com/royal-charter/the-inns

As well as researching the Temple Church, and blogging for the Success website, Catherine is also a crafter and photographer.



BRAVE HEART ART

"How do you create magic using your PC and AI"

I design my own Metal music album covers which have been my life's dream for several years now, but finding a way to produce them without Adobe was a question I did not have an answer to until recently.

Using the A.I programme, "MidJourney" and creating images via Discord has saved me a world of hurt from using Adobe software – something that I had had a lot of trouble with using back in college and uni due to its lack of required accessibilities for me to use it efficiently. Developing whatever kind of image you want is as simple as it gets;

You will need to create a Discord Account and Midjourney account before you start: Then in Discord in the text bar at the bottom of the screen, I just type in "/" and it will give several design options above. After selecting one of them (e.g. "Imagine", "Merge", etc.), I will either copy and paste a prefabricated description of the image – called a "prompt" – I have in mind from a Word document or select 2 individual images I had already created (which I will have saved from the gallery in my MidJourney account into a separate file) and see what a combination of them both looks like.

Within a matter of seconds – though it can depend on the simplicity or completely of the prompt –, the A.I design bot delivers not 1 but a collection of 4 square-shaped images and from there, they can be separated out into individual images where you can upscale them further such as getting stronger or more subtle versions from that one image (alongside other features). The individual images are automatically saved to my MidJourney gallery where they can then be saved as images into a separate file – later to copy and paste into whichever document you want to put them (e.g. Word, PowerPoint, etc.).

Website: www.midjourney.com
(you will need to pay a small fee to use this website)

Website: www.discord.com

By Callum Stewart



Synaesthete “We Three Kings”

A Synaesthete and a Christmas Carol "We Three Kings"

Those who have read Bravehearts issue 2 or attended the March 2023 conference, will have heard of chromaesthesia, which is a visual association of colour with music. Callum has this amazing ability and is thus a synaesthete, I am not but still finding it fascinating.

However, not only does Callum experience chromaesthesia, he also has perfect pitch. This means he can identify a given musical note just by listening to it. The only way I can identify a musical note is if someone tells me or it's written on a staff.

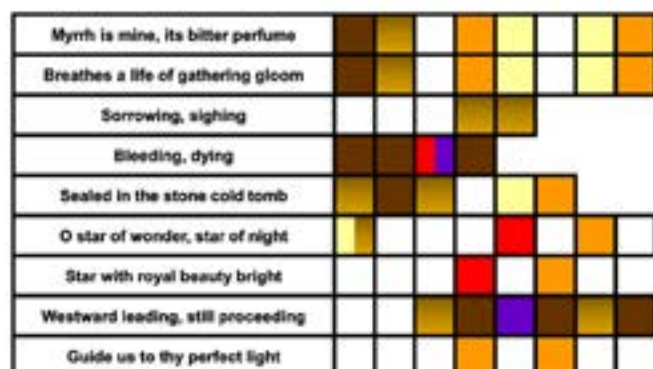
I recently asked him to listen to some music and tell me what he hears.



VERSE 2 & CHORUS



VERSE 4 & CHORUS

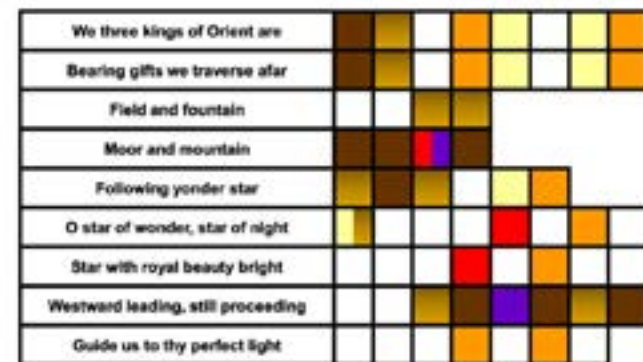


His detailed analysis was spot on!! (When I looked it up).

As the festive season is here, I asked him to use this talent on a Christmas Carol: "We Three Kings" and this was his response!!!

By Catherine Sutton and Callum Stewart

NOTE: The boxes that have more than one colour in them represent 2 individual musical notes - and their associative colour - across one syllable in a word.



VERSE 3 & CHORUS



VERSE 5 & CHORUS



Sophiyah Rayner - PART 1

Hello, I am Sophiyah and I was diagnosed with a germ cell brain tumour at the age of 7 years in 2009.

It all began when I became constantly sick, so my parents kept me at home and hired a nanny to look after me whilst they worked. She was amazing and made me the best cheese toasties! She noticed my eyes rolling and sat me down on the edge of the bed and asked me to look at her, but my eyes were looking in the opposite direction.

My parents rushed into hospital where I had several tests done including an MRI scan, which revealed a tumour.

I was transferred to Great Ormond Street Hospital where Dr Judith Kingston diagnosed me. I remember sitting outside the hospital room while my parents were talking to Dr Kingston about my treatment options. Later that week I was asked by the doctors if I understood what was happening, I said I had a germ cell brain tumour, they assumed I would say something like I had a "rock" in my head, but I always listened to what was happening.

Before my treatment plan began, I had a Hickman Line inserted. I was so relieved to have it, as I hated being pricked and prodded for blood. Shortly after that I started chemotherapy which left me feeling sick, so I ate whatever made me happy, which was a lot of chocolate! Today, like most women, it is my go-to food! When chemo was finished, I started radiotherapy and I had to wear a mask on my face. My teddy bear had one too as it made me feel better. The radiotherapy team at UCLH were amazing, as I disliked the smell from the machine, they created a fairy dance where they would dance around the machine with a lavender scent.

Travelling to and from London during the radiotherapy was very tiring so I was home schooled, and this allowed me to continue



my education. At the end of each day's lesson, my favourite part was my teacher reading me a "MR MEN" book. I really enjoyed them.

During treatment my mum was fighting hard to ensure I was given the help I needed, she consulted with Dr Helen Spoudeas at GOSH; together with the local authority, they got me statemented and several referrals to support the side effects of the treatment on the tumour.

I would not be where or who I am today without all the support I had. I can't leave out the support of my furry best friend, my family adopted a loving "staffy" from the RSPCA. He was with me throughout all my naps, and we watched loads of movies together; "he was my rock". I spoke to him through all the good and hard times. He lives on in my heart.

Secondary school was tough, but I had a lot of support after being statemented and Passmores Academy had an amazing SEN team. They were patient and understanding about my learning and medical requirements, to help give me the best education.

Like most SEN children, I got picked on for my differences, but I always managed to get through by smiling and embracing the positive side.

One thing I wish I realised, is the impact my illness had on my sister and what she went through being moved around all the time. She was so good, accepting all the change all the time. I would not have come out this strong without her; my parents always tried there best to ensure my sister and I got the help and support we needed, but nothing is easy when you have a child in hospital, as an adult now, I finally understand.

I would not have come this far without the love and support from everyone, especially my parents and sister. To this day their support has never left me. They are with me for every tear and fear I face and are my sole support system.

My life is still a roller-coaster and things are still not easy for me. Getting a job has been difficult with my medical needs, so I now work from home in my parents' business, which gives me the space and time, when I need it. I have a loving dog, a beautiful niece and a nephew on his way.

I have met my prince, who accepts and loves me no matter what obstacles I face and like any fairytale he will become my king on the 08/06/2024 when we get married.

Keep a look out for part 2.



02 MAR
Rehabilitation
LONDON

Success Annual Conference

**"Successful Destinations" at
1 Wimpole Street, London**

Save the date
02.03.2024

Bravehearts
LONDON
02 MAR 2024
SUCCESS

Peer to Peer
Mentoring

Success Airways
Success Annual
conference
CBX 63
to London
Boarding Area A
BOARDING
9 : 30 PM
GATE
D 09
SEAT NO.
C 33
Departing
9 : 55 PM

Success Airways
BOARDING PASS
FIRST CLASS
CBX 63
to London
Boarding Area A
BOARDING
9 : 30 PM
GATE
D 09
SEAT NO.
C 33
Departing
9 : 55 PM

Success Airways
FIRST CLASS
CBX 63
to London
Boarding Area A
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Departing
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Bravehearts
LONDON
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SUCCESS

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Rehabilitation
LONDON

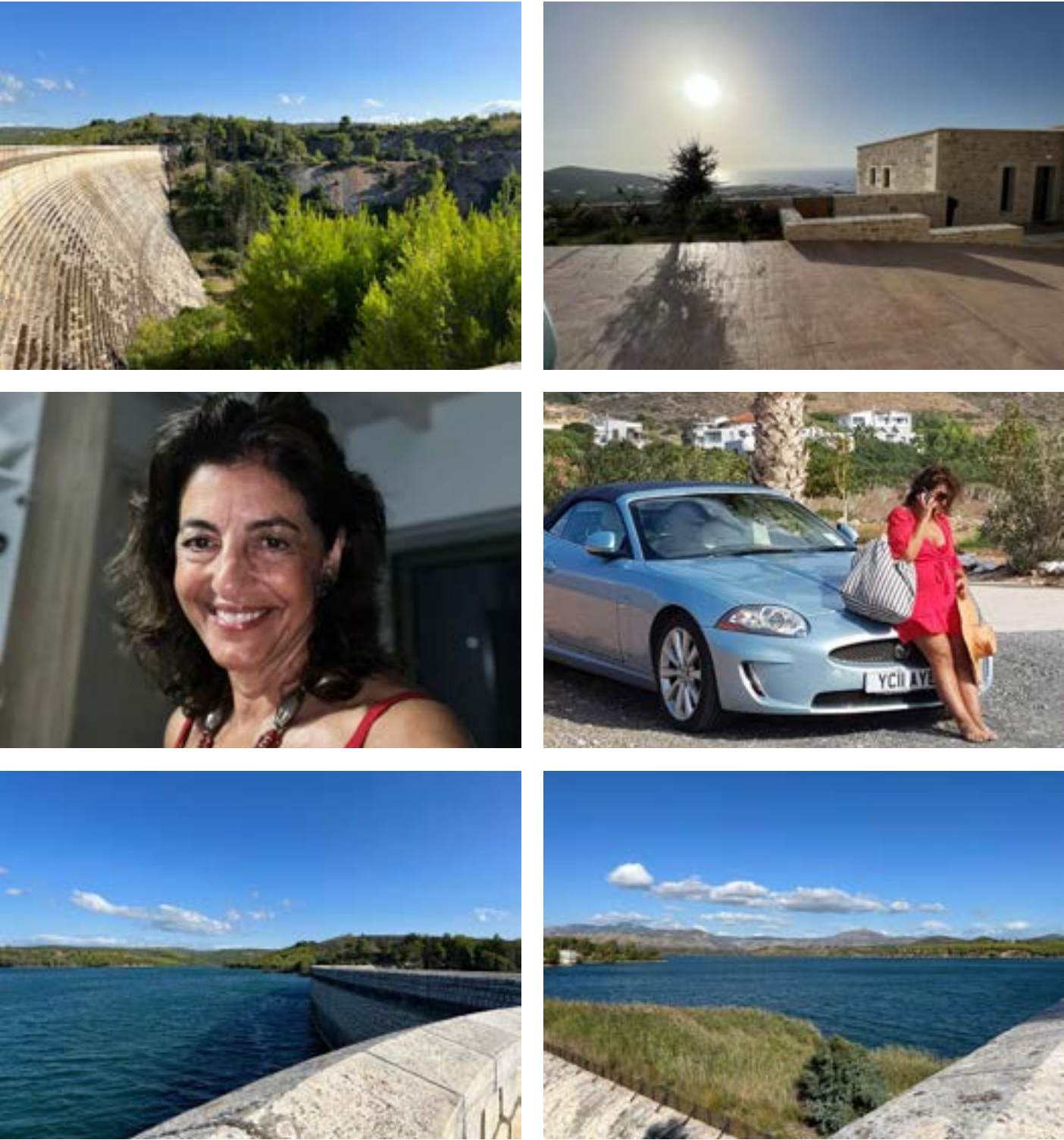
Achievements/Ambitions

We would love to show everyone your amazing achievements or, share an ambition you have.

All you have to do is drop us an email, info@successcharity.org.uk
Don't forget to include all the information we need to know, and attach a picture or two...

Annabelle just won an award for her miniature painting (it fits in the palm of her hand)

Dr Helen Spoudeas, our Charity's Founder has driven all the way from the UK to Greece on her own this September, in an adventure she has described as ; "14 countries, one woman and a bluebird I think!".



PUZZLES

Can you spot the 5 differences in our logo? Mark each difference with X

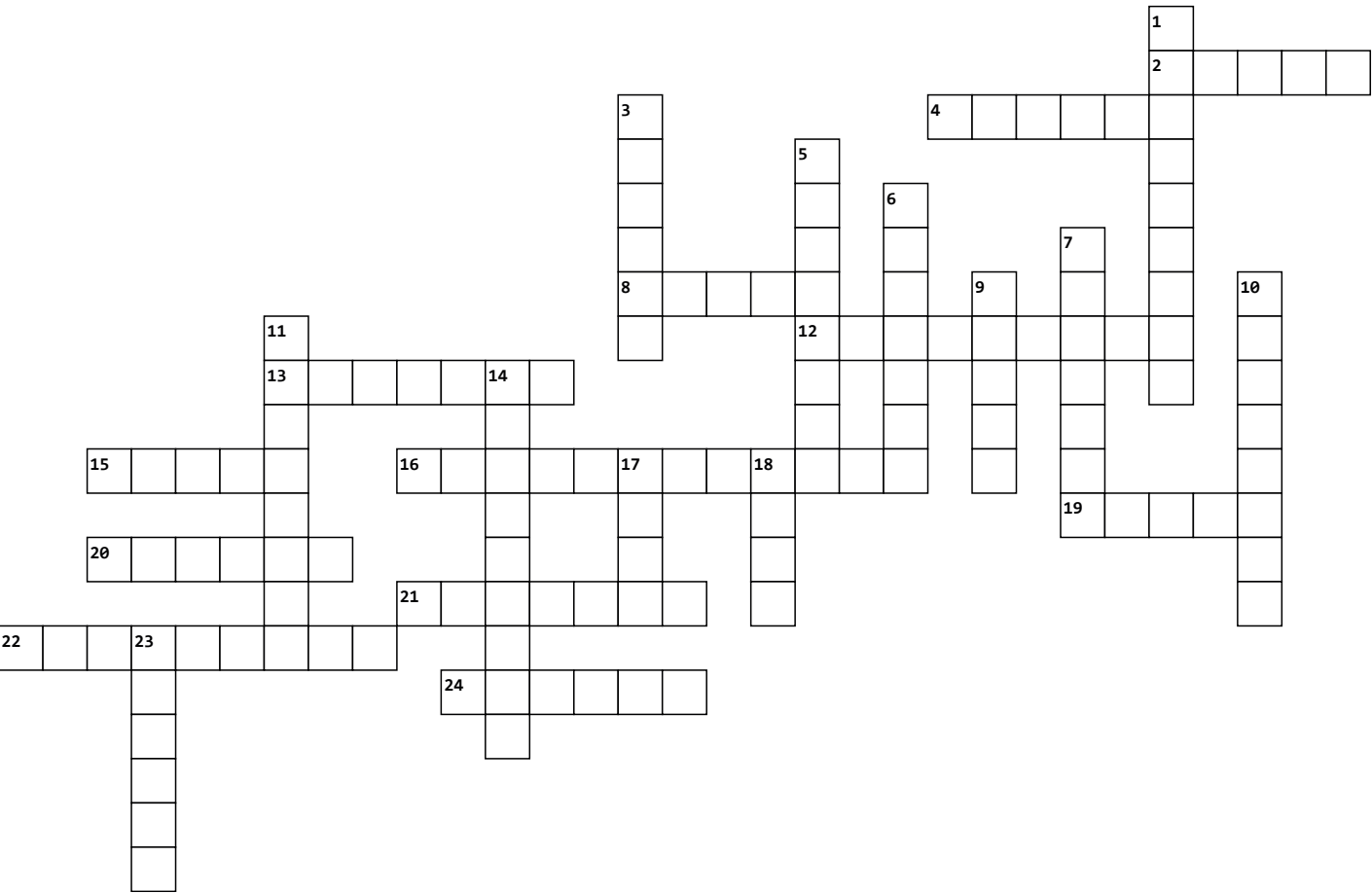


Wordsearch

E	Y	M	A	B	S	U	R	G	E	R	Y	R	I
C	P	T	I	E	R	I	R	S	T	R	E	S	S
A	A	O	A	C	Y	A	S	U	M	A	E	N	C
T	R	X	G	O	S	A	I	G	O	N	U	U	R
M	E	I	R	H	A	U	E	N	S	M	R	I	B
A	H	C	H	E	U	S	R	E	V	E	U	A	T
L	T	I	O	A	N	V	S	V	E	R	A	T	T
I	O	T	R	R	N	O	I	T	I	N	G	O	C
G	M	Y	M	I	E	E	I	S	E	V	N	E	R
N	E	E	O	N	E	M	A	S	I	R	A	T	B
A	H	G	N	G	E	M	S	O	O	O	R	L	C
N	C	R	E	M	E	M	B	E	R	A	N	C	E
T	R	G	S	Y	R	A	G	L	I	O	M	A	U
S	S	R	I	E	N	B	R	A	V	E	R	Y	V

- VISION
- TUMOUR
- HORMONES
- CURE
- MALIGNANT
- TOXICITY
- BRAVERY
- SURGERY
- HEARING
- COGNITION
- BRAIN
- CHEMOTHERAPY
- STRESS
- SENSES
- SURVIVAL
- GLIOMA
- REMEMBERANCE

Crossword



Across

- 2. Who helps Santa to pack all the presents at Christmas?
- 4. What do you use as a snowman's nose?
- 8. What bird do we like to roast for Christmas dinner?
- 12. What do we over indulge on at Christmas?
- 13. What is the name of the reindeer with the red nose?
- 15. Father Christmas' other name?
- 16. What is the night before Christmas called?
- 19. What bird do we most associate with Christmas?
- 20. What did Mary ride on to get to the manger?
- 21. What does Santa travel down on Christmas Eve?
- 22. What plant is often hung for people to kiss under during the holiday season?
- 24. What is the sweet, spicy holiday drink?

Down

- 1. Where was Jesus born?
- 3. What do you slide down snow with?
- 5. What do we use to make a Christmas wreath?
- 6. What is the name of greedy old man in Dicken's A Christmas Carol?
- 7. What do we pull and snaps at the Christmas dinner?
- 9. What plant do we put on top of Christmas pudding?
- 10. What do we love getting at Christmas?
- 11. What is hung on the Christmas tree?
- 14. What bird would you find in a pear tree?
- 17. What do we put up and decorate at Christmas?
- 18. What did the shepherds and 3 wise men follow?
- 23. What do Americans have in their Christmas dinner?

Once in a life-time

I am Youssef and I was diagnosed with a Grade 4 Glioblastoma when I was 6 years old in 2013. I was constantly being sick and off school, feeling dizzy and off balance. My mum took me to see the GP who prescribed antibiotics, but they did not help, and things became worse. So, by the summer when my mum noticed that the right side of my face was paralyzed she rushed me to A&E at St Marys where they started to investigations, such as a neurology review and an MRI scan, which found the tumour and then did a biopsy on it. It felt like it took so long to diagnose me and start treatment, but it actually only took 1 month from me getting sick to the diagnosis.



I had a brain haemorrhage when after the biopsy was taken, but they didn't not look into it as they just attributed it to the brain tumour. If they had looked into it, things would have been better with my coordination and movement and that is something I think that should be changed when they treat brain tumour survivors.

was a newborn. I still feel really guilty about taking her mom away from my brother and spending all her time with me, even though I know it was not my fault and she re-enforces that to me too. It is very difficult to come to terms with my feelings and although I attend counselling, I don't remember to mention this.

If I hadn't had a brain tumour and only had the haemorrhage, they would have provide rehabilitation for it, so I really lost out on that. This is something that still really frustrates me, but I want to make it better for others who maybe in the same situation someday as I was.

Let's ask Dr Helen Spoudeas about her thoughts on Haemorrhage?

When treatment started, I had to have chemotherapy and radiotherapy at the same time, which was very intense and exhausting and scary.

I have 2 younger brothers, and at the time my youngest brother had just been born. Most of my mom's time was spent with me and my brothers were passed around which must have been horrible for them. It was hard for my mom too, as she wanted to be with me but also needed to be with my brothers, especially as the youngest

Some family counselling would be helpful, for us to share our feeling openly and hear from one another of how we have coped and are coping now.

Maroon, (the middle brother) has not always been confident and who is to say this is not an impact of not having his older brother around more, but with counselling from school and the support of my family and myself he is getting more confident every day and he is keen to do a skydive challenge to help raise funds for Success Charity. He has had a lot to deal with at such a young age, seeing his older brother in an out of hospital and then nearly dying.

I have had 2 further relapses since I was diagnosed and I will have more, which keeps me thinking that I might die any day. I have been reading all about my type of cancer and that it is one that continues to recur and which I will need to live with. So, counselling about how to deal with more

side effects will be helpful for my future.

I really wanted to see my family in Lebanon just one last time, so at the Success Charity picnic in June 2023, I told my story to a lovely lady about how much it would mean to me to see them all one last time and then we received an incredible donation from her which meant the whole family go fly to Lebanon for the summer holidays. It was a dream come true for me and I cannot express how grateful I am to the donor.

It meant that I was able to say goodbye to my uncle who died the same week we arrived and then we were able to attend his funeral. I really enjoyed the precious time I spent with him before he passed away. We did go to a few places while we were there, like the "Roman Ruins" and a village by the sea, but most of my time was spent with the family who understand and support me. I don't feel any pressure from them to talk about things if I don't want to and at the same time I talk when I want to, unlike counselling which has a time limit. I also got a chance to be more social, unlike in the UK where I don't have a lot of friends close by.

I most enjoy meet up with other survivors who get me and vice versa, so when there is a Success event, I look forward to attending it.

Written by Youssef Ghanem



Survivors Group

Are you feeling isolated, alone or not sure how to connect with others?

Then why not join the Success family. We have a weekly Survivors Group that meets on zoom **(every Wednesday at 17:15 pm)**

We also have a Survivors Group on Whatsapp.

For more information email Elaine; **info@successcharity.org.uk**



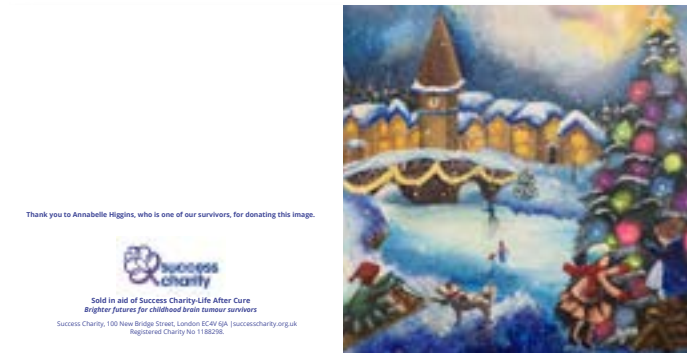
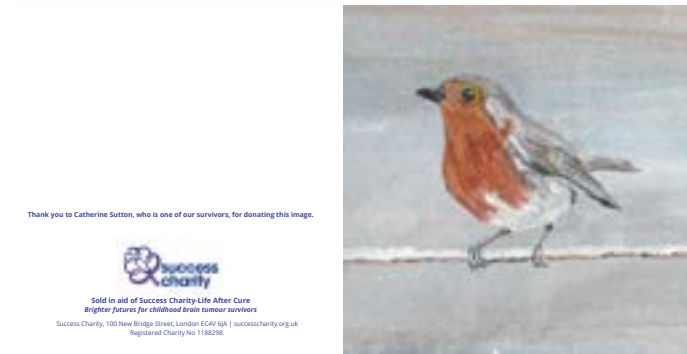
Submission Notice

We hope you have enjoyed our survivors perspective on what they have been through and how they have overcome their many challenges to date.

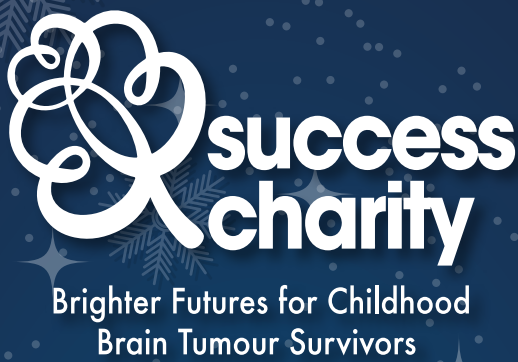
We are happy to have all of your different contributions; which could be to write your survivor story, draw us a picture, draft a poem, give us a short story or an article on something that you really enjoy or are fascinated by, or send in your suggestions of what you would like to see in one of the future issues.

To do this, please email the editor at info@successcharity.org.uk with your submissions. Writing your survivor story can be tough, so if you are feeling apprehensive about this, let us know and we will arrange an interview with you to get your voice heard. Braveheart friends and family, we want to hear all voices, so please do send in your story of what it has been like to have a sibling, friend or your child as a Survivor. ALL voices need a stage, so don't be shy, please share your story with us.

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