

An extraordinary story

By Kimberly M. Wallgren

Kimberly Wallgren lives in Indianapolis, Indiana (USA). Her father, Dallas, was diagnosed with an anaplastic ependymoma in 2002. Kimberly is a member of the Collaborative Ependymoma Research Network's (CERN) Awareness and Outreach team. Here, she tells "Brain Tumour" magazine her family's moving and inspirational story and describes how Dallas' diagnosis inspired her life's work.

I currently support the Patient Awareness and Outreach component of the Collaborative Ependymoma Research Network, commonly referred to as the CERN Foundation.

My background and ultimately how I got involved stems from the deeply personal and life changing event of my father's diagnosis with a rare type of brain tumor called ependymoma when I was 21 years old. In fact, my connection to brain tumors truly started before my father's diagnosis with a brain tumor and begins with my mother's story.

The journey begins

My mother, Janice, was young and in love with a handsome man named Joe. The two were married in South Carolina and soon after left for Newark, Ohio to start a life together where Joe took a job as an engineer and my mother as a teacher.

After a few years of marriage, Joe was diagnosed with glioblastoma. They both decided that a child would bring joy to this hard time in their lives and would be an ultimate gift of love. Four short months after their darling son Anthony was born, Joe lost his battle to glioblastoma. My mom was now a single mother and survived on her faith and the support that people gave her.

Over a year later, through dear friends, my mom was introduced to my dad, Dallas. The two found solace in each other and saw a hopeful relationship



Above: Kimberly Wallgren representing the CERN Foundation at the 2012 Society for Neuro Oncology (SNO) Meeting in Washington, D.C.

ahead. They were married and later on that's when my story officially started!

History repeats itself

Our new family was exciting, imperfect, meaningful, and different. We all humbly came to the understanding that my life and our family were made possible because of Joe's death and he would forever be intertwined with us. But cancer was really not an apparent part of our lives until 21 years later when we all started to notice changes in Dad. In fact, if it weren't for Mom's knowledge and first-hand experience of the symptoms of brain tumors, Dad's diagnosis would have been much more delayed and potentially associated with a worse outcome.

I knew on July 17, 2002 that my life's work would somehow be linked to helping those with brain cancer. I graduated with a B.S. in Marketing Management from Virginia Tech in 2003 and took a job in marketing with Blaine Pharmaceuticals, a magnesium supplement company that sold a product for people on cisplatin, a chemotherapy drug that Dad took.

Next, I moved into the neurosurgical device industry where I was a product manager for Integra Life Sciences specializing in Mayfield cranial stabilization equipment, a device that had been used on Dad twice. The most thrilling component of this job was my experience in the operating room with the neurosurgeons and perioperative nurses. I also supported many practical courses across the country which gave me the satisfaction of helping to better the industry in some way, no matter how small.

Then after my father's recurrence in 2006 I was determined to get even more involved and asked to take an active role in the newly founded CERN Foundation. I initially started in a marketing role and helped to create the marketing strategy, support materials and website. I have transitioned into a different role that is more focused on developing our tight-knit ependymoma community through communication, referral support and

bridging the patient and professional community together.

My role at CERN

I help provide referral information to patients and medical professionals, facilitate physician to physician consultations, and try to find answers to specific ependymoma questions that I receive. I also direct patients and caregivers to our website, which offers a lot of great resources to the ependymoma community including detailed information on the disease; questions to ask your doctors; updates on published research; external online resources, Ependymoma Outcomes (EO) Project survey; inspirational stories; and ways to get involved in the local community with our awareness day kit.

Beyond our website, we have a vibrant Facebook page and Twitter account with a lot of activity and large follower base. Staying connected with the CERN foundation is very important as we ►



Above: Kim Wallgren with husband Jake and their three children



Left: The entire family in Hawaii in the summer of 2012. Left to right: Jake, Kim, Dallas, Janice and Anthony with Jake and Kim's three children.

embark on new projects and research initiatives.

I am contacted by patients as well as caregivers. Of course within the pediatric ependymoma community the caregiver is always the one to contact us but within the adult ependymoma community patients and caregivers alike reach out for information.

We also get inquiries from members of the international ependymoma community. While we cannot offer second opinion information over the phone and via email, we do try to answer specific questions about ependymoma that we get and direct the person to the website for further information and resources. We also offer a physician-to-physician consult if desired and kindly ask for the treating clinical team to initiate communication.

The journey is overwhelming

When families are newly diagnosed, the

overwhelming amount of information can feel extremely intimidating. Learning the medical terms - or even how to properly pronounce the name of the disease itself - takes a while. But eventually patients do become familiar with this new language and it becomes easier to discuss their disease freely.

We took a very logical approach of communicating information by starting with the basics of ependymoma, then introducing diagnosis, and lastly, explaining treatment information. These are the first three topics available under the "Patients and Caregivers" section of the website.

The other section of the website that is very popular is the CERN centers map where you can identify all of the pediatric and adult centers that are affiliated with the CERN Foundation. You can obtain the names of CERN members at the listed institutions and link to the organization's website.

Ependymoma Awareness Day 2013

We are excited to announce the 2013 Ependymoma Awareness Day on April 18. This is a great event that allows and encourages people to host their own local awareness day.

Last year, we had great success from people overseas hosting a special ceremony or event in a way that was personal to them. Some of these families emailed photos and newspaper articles after the awareness day so we could display them on our website. Please check out the CERN website for more details on this and how you can even ask your local government to get involved in recognizing the Ependymoma Awareness Day. ■

The CERN Foundation's website can be found here: www.cern-foundation.org
For further information, contact: kwallgren@cern-foundation.org

Palliative care - travelling First Class

IN 2012 a Committee of the Australian Senate studied palliative care services and received submissions from a number of people. One of the people chosen to give verbal evidence was "Ms Kim McCartney", a patient with a brain tumour. In its report the Committee quoted a powerful section of Ms McCartney's evidence in which she described how she viewed palliative care - as an opportunity to travel First Class, rather than Fourth Class.

This is what she said:

"Ms McCartney: One of the things when I was diagnosed was that so many people were like: 'Oh, you poor thing.' It occurred to me one day that if someday [somebody] had walked up to me before I was diagnosed with this and said, 'Hey! Do you reckon you might die one day?' My answer would have to have been: 'I reckon; I'm a good chance, yes.' The only difference between the Kim of then and the Kim of now is that I have had confirmation of what

I already knew. I have not changed; I am still no different to anybody else.

Don't ask me when; I don't know. I might know how-perhaps. That is the only difference between me and any of you sitting here. I am exactly the same as everybody else. Like I said, it is just that I have had confirmation of what we all know... I think that if people could understand that, it would take [out] that whole taboo thing about: 'Oh, tumour-poor thing.' I am the same person. In the beginning, when people said, 'Oh,' I used to pat them back and say, 'It's okay; you've got a ticket too.

You're on a winner just the same as me.' It is the truth! People look at me as if to say, 'Oh.' You can tell that they have never actually looked at it like that. It is like: 'You're on a winner; it's all good.'

But, yes, I think that there does need to be some sort of campaign so that people actually do realise that death is universal - no one is exempt. If people could get their head around that they might be able to start coping

with the thought of palliative care.

I remember saying to the hospice one day - they had come around and we were having a chat - 'I'm putting something out.' They said, 'What's that?' I said, 'I'm on a train; I can't get off. I know where the destination is and until the train stops there I can't get off. But I do have a choice. I can choose to travel third class, on a splintery wooden bench with no back on it and my feet just not quite touching the floor, or I can opt to go first class, with the Jason recliner, a nice cuppa and a magazine - I'll choose first class.' I said to the girl: 'And that's why you're here.' I meant it.

I do have a choice on how I can exit this world, and I am going to choose the most comfortable. That is my best explanation of palliative care: choosing to exit first class, not fourth class." ■

(Source: Australian Senate, Community Affairs References Committee, Report, Palliative Care in Australia, October 2012, pages 194 and 195.)