

ELECTIVE (SSC5b) REPORT (1200 words)

A report that addresses the above four objectives should be written below. Your Elective supervisor will assess this.

St. Jude Children's Research Hospital Elective in Paediatric Neurology and Neuro-oncology

I undertook a four-week paediatric neurology and neuro-oncology placement at St. Jude Children's Research Hospital (SJCRH) in Memphis, Tennessee. This world-class institution is renowned for its impact on catastrophic paediatrics conditions and developing novel treatments based on rigorous empirical research. Notably, since its creation in 1962, the survival rate for childhood cancer increased from 20% to 80%. Its main research focus is in cancers, SCD, genetic disorders, immunodeficiencies, neurological conditions and complications from treatment. Unlike most hospitals, SJCRH has 78 inpatient beds and is largely run through outpatient clinics, resulting in 7,800 patients/pa being seen. Whilst most are seen for continuing treatment, numerous are also monitored for on-going longitudinal research or follow-up studies.

My main intention for this elective was to discover more about these subspecialties as I had enjoyed my paediatric and neurology rotations during medical school. I was keen to learn about the US healthcare system and how medicine is practiced differently to the UK to aid in my subsequent practiidecision-making for future career development. On elective, I attended outpatient clinics in paediatric neurology and neuro-oncology. I was given the opportunity to join in with the rest of the team with in-patient consults and provided a lot of teaching. I was also able to clerk and examine patients and discuss the management plans with the team. Additionally, I attended the weekly brain tumor practiomeetings where challenging and interesting cases were discussed.

1. There are similarities between the pattern and prevalence of paediatric neurological conditions between the US and UK. Epilepsy/ seizure disorders are the most common neurological disease seen in children particularly in the US and UK. Comparing the Royal London and SJCRH, common neurological presentations seen were epilepsy and seizure disorders, development disorders (including Autism Spectrum disorder), movement disorders and headaches.

In the UK, cancers are the most common cause of mortality in children, with leukaemia being the number one cause followed by CNS tumours. However in the US, due to advancements in treatment, children are less likely to die from CNS tumours. As SJCRH is a specialised centre, I was able to see different types of brain tumours and rare conditions including infantile west spasms, Sotos syndrome and Aicardi syndrome that I would not have been able to see in the UK.

2. In the UK, the National Health Service (NHS) funded by the UK taxpayer delivers a healthcare service that is free at the point of access. Private medical care is available for paediatric cancer and neurology but most patients are treated through the NHS. Conversely, the US healthcare system is insurance-based with some allowance by Medicare and Medicaid for the elderly and those on public funds. Following the advent of the affordable healthcare act in 2010, healthcare insurance became more affordable allowing for more people to access Healthcare. Although provision of healthcare in the US relies on medical insurance, I am going to focus on the unique model of healthcare funding and provision by SJCRH, which is dissimilar to most US hospitals. SJCRH is largely funded by public donations, in particular ALSAC (American Lebanese Syrian Associated Charities), which contributes to over 75% of the \$2.4 million daily funds required to operate the hospital. The remaining 25% comes

from federal grants through the National Institutes of Health and National Cancer Institute and from medical insurance. Therefore SJCRH does not charge its patients for the healthcare services it provides but it will accept insurance for services covered by it. However standard insurance does not cover many of the specialized treatments and services available at SJCRH. Unlike other US hospitals, SJCRH offers free transportation, on-site schooling, meals and specially designed accommodation based on estimated length of stay to all its out-of-state or global patients.

For paediatric patients to have access to these neurology/cancer services in the UK, it is on the basis of a referral to specialists from their general practitioners (GPs), the equivalent to family doctors in the US. Generally, in the UK, a GP is responsible for the care of a child, however in the US, the health of the child tends to be under a paediatrician who manages their healthcare until 21 years of age. In the US it is therefore, the paediatrician who mainly refers the child to the appropriate team. However, there is a push towards more UK community-based paediatrics, which not only will relieve the burden on GPs but may also improve the level of care received by children.

Due to the increased funding and higher quality services in the US, SJCRH is able to offer a more holistic treatment approach than in the UK, for example music and art therapy and regular themed days for the patients to get involved in. Almost all hospitals in the US have Child Life specialist who work with the patient and their families to provide emotional support and counseling, explain medical/ surgical procedures to children and act as an advocate.

3. From what I have observed, there is an enormous similarity between the conservative, medical and surgical management of neurological conditions in the UK and the US. This is likely due to similar research being used in the UK and the US to govern guidelines for disease management. Certain treatments that are of considerable expense are often less used in the UK, for instance botox injections for chronic migraines or the use of nerve blocks, where the NHS has clear and very stringent guidelines and protocols restricting its use on a selective group of patients. Conversely, SJCRH will take patients who either have no established protocol for treatment or have failed the standard protocol of treatment. Due to the large body of research being conducted at St Jude, many patients take part in clinical trials and are on non-protocol treatment plans.

The US has a greater selection of treatment options for neurological and neuro-oncological conditions. Indeed many brain tumours are treated by specialized treatment regimes including radiation delivered in various forms such as gamma knife stereotactic radiosurgery, intensity modulated radiation therapy (IMRT) and proton beam therapy. Until recently many of these treatments were unavailable on the NHS, and many families would have to fly to the US for treatment. However in the past 5 years there has been development towards improving cancer treatment options available on the NHS. By 2018, 3 proton therapy centres will be operational in the UK for both adult and child populations. The UK in comparison also has fewer and limited centres offering IMRT. Other therapies, such as Gliadel carmustine wafers for brain tumours, have gone out of fashion for use in children in the US but are still used regularly in the UK.

4. It became apparent to me that I had only seen a small selection of paediatric neurology in London, limited to epilepsy and seizure disorders, autism spectrum disorders, headaches and movement disorders. IN SJCRH the paediatric neurologists see a larger range of conditions and are often called to consult patients suffering from neurological complications of chemotherapy agents or radiation. I have immensely enjoyed my elective and hope to pursue a career in paediatric neurology in the future.