## Extract from Hansard

[COUNCIL — Wednesday, 1 September 2021] p3270b-3271a Hon Matthew Swinbourn

## CHILDHOOD CANCER AWARENESS MONTH

Statement

HON MATTHEW SWINBOURN (East Metropolitan — Parliamentary Secretary) [6.26 pm]: Today is 1 September and many of my colleagues who worked with me in the last term of Parliament will know that on the first sitting day in September I always bring to everyone's attention that September is Childhood Cancer Awareness Month. It goes for the whole month, naturally, and is an opportunity for us to talk about childhood cancer to raise awareness and to make sure that we are focused on fundraising, because it is through research that we will get better treatments, and through better treatments we will get cures. Members will see me wearing this gold ribbon on my lapel. Gold is the colour that represents childhood cancer. Places will be lit up in gold over the month. If members see that, I hope it reminds them to think about childhood cancer and the impact it has on some of our most vulnerable people in the community.

Sadly, about 100 children die each year from childhood cancer. It is the leading cause of death in children under the age of 14, so we have a continuing battle. As we all know, we are going through a pandemic in Australia and globally and that presents issues for people suffering from childhood cancers because all childhood cancers are considered to be rare diseases and the options for treatment are not always available. Many children, including my own, seek access to drug trials. Often, those drug trials are the only things that offer a lifeline of hope for treatment and a cure. Drug trials are often conducted in other parts of Australia or internationally and there are strict rules around how they are conducted. Often the patient must travel to the place in order to participate. Two years ago my son Mitchell travelled to Brisbane on a fairly regular basis to receive treatment in a drug trial, which unfortunately was not successful, but he could not receive any of the treatment or have the blood tests or scans here in Western Australia. He had to keep flying back to Brisbane to do that because that was part of the trial's protocol. Members can imagine that if they wanted to access a drug trial in Germany, the United States, or Great Britain at the moment, they could not travel to those places to do that.

Every child going through treatment for cancer is immune suppressed and, therefore, cannot be exposed to the COVID-19 disease in all its variants. In our family, both my wife and I have been vaccinated. My wife had AstraZeneca and I had Pfizer. Our eldest son, Harrison, and our youngest son, Darcy, are booked in because Mitchell cannot be vaccinated against COVID-19. We all get letters from people talking about how bad the vaccine is and this, that and the other, and it is a particularly difficult thing for me to read because it certainly strikes home for us.

Many members have been very courteous and have asked me how Mitchell is going. He is now 16 years old and is going reasonably well. He is participating in a new immunology trial to try to get his immune system to attack his cancers. As part of that, a couple of weeks ago he had to have a resection of one of the tumours in his lungs to get a sample for the trial. He had to have a port line and a peripherally inserted central catheter put in. I spoke about this earlier today and said that he was in hospital for 11 days recovering from surgery and dealing with the side effects of his new drugs. All the drugs that are given are, of course, a form of poison because they are trying to poison the tumour and stop it from replicating and spreading throughout the body.

As I said, Childhood Cancer Awareness Month is particularly personal for me. When you have a child who goes through cancer, you become part of the broader community of childhood cancer survivors and some of the families whose children unfortunately have not survived. It is a very supportive community, but it is very hard and obviously people in the community feel up and down. Groups such as the Kids Cancer Support Group do wonderful things. For example, on a Saturday morning they will come around and get you a proper coffee—not Nescafe blend 43 or something along those lines—and they have a pizza night on a Friday night. Sometimes it is the little things. Groups such as the Kids Cancer Support Group need funds to support those activities, so during Childhood Cancer Awareness Month, I hope that members will make a donation, small or large, to a childhood cancer charity that either supports research or supports families. As I said, gold is the theme and it is #GoGold for those sorts of things.

In covering off on Mitch, he is going okay. If members saw him, they would probably think he is a reasonably normal 16-year-old teenage boy. He certainly has a bit of attitude, which is always very encouraging.

Hon Kyle McGinn: Like his father!

## Hon MATTHEW SWINBOURN: Too right!

He does not go to school and he struggles with a lot of other bits and pieces. He tires very easily, but he has great character and a great sense of humour.

This leads me to announce that with my parliamentary colleagues Hon Stephen Pratt and Hon Donna Faragher, who is not here at the moment, we have established the Parliamentary Friends of People with Rare and Undiagnosed Diseases, and this is a plug for it. All members—it is a nonpartisan group—are invited to the launch on 19 October. We have reached out to the broader rare disease community and we will be bringing some of its members to Parliament. I ask all members here—it is not a sitting day, but it is an estimates hearing day—to make time in their diaries to attend the launch and meet people who suffer from rare diseases, children who have cancer and the

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researchers and health officials who work in those areas to find out more about their needs, because it is only through education and awareness that we will find full treatments and cures. Thank you everyone.