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MINISTER FOR HEALTH AND AGED CARE

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SUBJECTS: PBS listing for Cystic Fibrosis medicine; Calls for Peter Dutton to sack Barnaby Joyce for his comments; Ministerial reshuffle.

MINISTER FOR HEALTH AND AGED CARE, MARK BUTLER: Good morning everyone. And it's such a beautiful way to start the week to be joined by a number of families from the cystic fibrosis community. We've just been talking with a number of them including Heath, whose mum Ashley is here and is going to say a few words. So welcome to everyone here on a brisk but beautiful Canberra morning. Also Jo Armstrong who leads the CF community, the cystic fibrosis community, through the terrific organisation, Cystic Fibrosis Australia, that is just such a compelling, powerful advocacy group, harnessing the ambitions of all of these families and the many, many others beyond Canberra to get the sorts of lifechanging treatments that we're able to announce today. And also Professor Claire Wainwright from Brisbane. She's going to take all the difficult questions this morning about this amazing drug that we're announcing for further listing today.

Cystic Fibrosis affects about 3,700 Australians. It's an inherited genetic disease that, from birth, has a very profound impact on those who live with it. It leads over time, in a progressive way, to very serious lung complications, and sometimes to death. It requires very significant treatment, almost on a daily basis, including surgeries and hospital treatment for kids as young as the ones who have joined us today. There is, though a genuinely lifechanging, lifesaving treatment out there called Trikafta, which is a drug produced by the pharmaceutical company, Vertex. It covers a particular mutation that impacts about 90%, I think it is, of all of the CF community. And progressively over time this drug has been listed on the PBS for different age groups.

Last year, we listed this drug for six to 11 year olds, and it has had a profound impact on those families. I've talked to parents really who, within 24 hours, noticed this amazing change in their child. I've talked to one dad who every morning had to go in and physically carry his daughter out from bed. And when he went in there, literally the morning after she started taking Trikafta, she wasn't there. And he got very worried until he went into the living room and realised that for the first morning in so long, she had got herself out of bed and been able to go out to the living room and start sitting on the couch watching TV. It is that immediate, it is that profound. It allows these children to go on to live long, happy lives and to enjoy their childhood, in the same way all their other school friends, who don't have cystic fibrosis,

are able to do. I was talking to one kid here who's representing the ACT in cross country running, after starting to take Trikafta in the last 12 months.

I'm delighted today to announce that from this week, from the first of August, I have to also be listed on the PBS for children aged two to five years, after a recommendation from the independent Pharmaceutical Benefits Advisory Committee. This will have a huge impact on those families. It will allow families to get the benefits of Trikafta earlier than otherwise would be the case, instead of waiting till the child's sixth birthday. And because this disease is progressive, the earlier you're able to get the lifechanging impacts of this Trikafta drug, the better their lifelong chances are going to be. So I'm delighted we've been able to make this listing. And I reinforce that, without this listing, this drug would cost families about \$250,000 each and every year. So obviously, this makes this drug accessible and affordable for those families who are now going to be able to access it because of this listing - a number we think is in the order of 330 families able to access this drug for their two to five year olds.

I want to thank obviously the Department and the company, for their quick negotiations to get us to this point: able to announce this listing. But I also want to thank Jo Armstrong, and the CF community. All those families who, in addition to doing all of the hard work you have to do with nebulisers and drug treatments for your children to enable them to go about their lives in some way. You've been able to talk to MPs, talk to public officials, come to Canberra, and just make really clear the enormous lifechanging impact that the listing of this drug would have for your children. That really has been a very compelling campaign that CF Australia has led, with the support of all of these families. So I'm going to hand over to Ashley. Thank you for coming.

ASHLEY HAYES, MOTHER TO 4-YEAR-OLD HEATH: Firstly, I just want to start by saying thank you to Minister Butler, for listening to us, listening to our voices, reading our letters, and just making this happen today. A huge thank you to Vertex for creating a miracle. We could never have imagined that we would be looking at a life where we could take three tablets a day. A huge thank you to Jo and Cystic Fibrosis Australia, for giving us a voice when sometimes we can find our own. Because there are times when it is hard. And also a massive thank you to the Sydney Children's Hospital network, on behalf of our family. I truly do believe we have some of the best paediatric care in the world. And it's affordable. It's just that where we don't need to worry about it. So a massive thank you.

A few people have said today, what does this mean to us? In my family, it means hope. Hope that every time he coughs, we don't need to worry: "Is two weeks hospital coming? Do we need to do more treatment?" Hope that no family will have to sit, when they have a newborn like Heath was, and worry will they live a long life. So today, I'm just so hopeful and so grateful for everyone that's made this happen. Our family will sleep a lot better tonight. And we just can't wait to keep planning the long life for Heath that we know he's going to have. I also just want to say thank you to those families before us, those parents that advocated and those with cystic fibrosis that we've lost along the way. So thank you so much for everything everyone has done. You have changed our lives today. Thank you.

JO ARMSTRONG, CEO, CYSTIC FIBROSIS AUSTRALIA: I can't say too much more after that. But good morning, everybody. Jo Armstrong, the CEO of Cystic Fibrosis Australia. Cystic Fibrosis Australia is the national patient advocacy organisation. We have long been advocating for Trikafta. We have seen that Trikafta has benefited adults already and older children. And today it is great news that more than 300 young children will have access to Trikafta because of this listing. Access to early intervention is critical for young children. We know that it does slow the disease progression and improves the trajectory so

that, ultimately, children will have longer, healthier lives as a result. Trikafta is a very expensive medication, and it is not accessible without it being listed on the PBS. So today's announcement means that it will be affordable for families, which is great news. My sincere thanks to the Minister, to Vertex and to the whole CF community who've been advocating alongside us. It really is a joint celebration today. And we certainly hope for the future for 300 young kids. So thank you.

PROFESSOR CLAIRE WAINWRIGHT, ROYAL CHILDREN BRISBANE: It's a hard act to follow, after so many amazing people have spoken before. I'm a physician that has looked after children with cystic fibrosis for more than 20 years. And I've seen such enormous changes. The first 1,000 days of life in young children sets the trajectory for the rest of their life. So today's announcement and the ability of these young children to reset their trajectories, I think brings amazing hope that this lifesaving, lifechanging medication will be available right across Australia to so many children with cystic fibrosis. And hopefully that will bring so many of them a longer life and a much healthier life, to lead a productive and exciting opportunity in their lives. So my thanks to Minister Butler and to all the children who have also partaken in research to do these studies that have led to this listing. And all the clinicians, the families, it's an amazing opportunity for these young children. So my thanks to everybody. Thank you.

BUTLER: Thank you. I might take questions on this listing before there are any other questions.

JOURNALIST: Just why has it taken so long for the listing to extend to younger children, as opposed to those over the age of six in the first place?

BUTLER: I might ask Claire to respond to that. But it's not unusual for a drug to go through a process of demonstrating efficacy and cost effectiveness for different cohorts and have the listing extended in a progressive way. So originally it was listed for children 12 years old and older. Last year we extended that listing on the advice of the Pharmaceutical Benefits Advisory Committee to six- to 11-year-olds. And then we received further advice that the drug will also be efficacious and cost effective for children aged two to five. But I might ask Claire Wainwright if she can add to that.

PROFESSOR WAINWRIGHT: There are clinical trials that are done at each age. And so that helps to provide the opportunity for people to understand safety, the right drug dosing, and what it's going to do for the health of patients. And so it's really important that we look at that across the different ages. And it starts usually with adults and comes down in age. So that's really why there's been this change over time. And now you've got the opportunity for these two- to five-year-olds. So I think that's fantastic.

BUTLER: Before we go to other topics, I'd like to say something about the remarks that Barnaby Joyce made yesterday at a rally, where we use very explicit language about the voting process, effectively being a way in which voters could load magazines with bullets, to use to say goodbye to the Prime Minister, goodbye to the Queensland Premier and also to the Minister for Climate Change.

I have to say that at a time when the head of the Federal Police has testified before this Parliament about a sharp rise in explicit threats against Members of Parliament, and within just a fortnight of the assassination attempt against former President Trump, it is simply extraordinary that a senior frontbencher would use such explicit, violent language about the Prime Minister of this country and other senior political leaders.

Now I note that Sussan Ley, the Deputy Liberal Leader, this morning failed to condemn Mr. Joyce's remarks. If Peter Dutton has any sense of strength as a leader and any sense of responsibility as the

alternative Prime Minister of this country, he will sack Barnaby Joyce for this simply unacceptable, violent language that he's used at a public rally.

JOURNALIST: On the reshuffle, Andrew Giles, Clare O'Neil and Julie Collins have all been moved on from their original roles, is this an admission of failure?

BUTLER: The Prime Minister has addressed the reshuffle. I am incredibly excited to be able to move forward from today – I think they're being sworn in, as we speak – with the sort of experienced, energetic team that the Prime Minister has been able to pull together in the reshuffle.

JOURNALIST: The Prime Minister before the reshuffle was saying that it was on the basis of the retirement of Linda Burney and Skills Minister Brendan O'Connor. Now skills has been taken out of the Cabinet, so it's not exactly replacing like for like, for instance. Why has that portfolio be taken out of the Cabinet altogether?

BUTLER: The Prime Minister has addressed this. Skills and Training remains a part of the Employment and Workplace Relations portfolio, that continues to have Cabinet representation through the new Minister: Minister Murray Watt.

JOURNALIST: How does it make sense that Home Affairs, the lead national security portfolio, has no control over ASIO, the AFP, and other agencies?

BUTLER: The AFP was shifted back to the Attorney General's Department at the last election after Labor came to government, and ASIO has returned to the place that really it existed for the vast bulk of its history, until 2017, for decades in the Attorney General's Department.

JOURNALIST: But do you think it makes sense that Home Affairs has no control over such agencies?

BUTLER: The Prime Minister has addressed this; I don't have anything further to add.

JOURNALIST: Do you think a reshuffle like this, two years into government, promotes stability?

BUTLER: The Prime Minister has made the point that it is a very, very long time - I can't remember a time where a new government went two years without a reshuffle. I'll point out that Peter Dutton has already had four reshuffles of his shadow frontbench and, as I said, frankly, he should have a fifth reshuffle, because he should sack Barnaby Joyce, because of the explicit violent language that he used at a public rally yesterday. So this is a Government that I think has a strong foundation of experience and stability. Our first two years of government have demonstrated that very, very clearly. But it's also one that's bringing in new talent. You see that in the reshuffle yesterday.

JOURNALIST: Barnaby Joyce has apologised for using that metaphor. Do you think he should still be sacked, regardless?

BUTLER: I've seen his apology. It was the sort of apology you get from, frankly, a stubborn child. I mean, this was an incredibly irresponsible use of violent language, at a time where, as I said, the head of the Federal Police has testified to this Parliament that there's a sharp, worrying rise in threat levels against Members of Parliament. We have seen, only in the last fortnight in the United States, a failed assassination attempt against former President Trump.

The idea that a former Deputy Prime Minister would use explicit language at a public rally about bullets and magazines being loaded to say goodbye to the Prime Minister and other senior political leaders is simply extraordinary and utterly unacceptable. If Peter Dutton has any strength as a leader of this Coalition, any sense of responsibility as the alternative Prime Minister of the country, he must sack Barnaby Joyce today.

Thanks everybody.

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