

27 April 2022



Kia ora

# Your Official Information Act request, reference: GOV-016892

Thank you for your email of 22 February 2022, asking for the following information under the Official Information Act 1982 (the Act):

1. All internal correspondence within the Ministry of Health and ACC relating to the Petition of Denise Astill Petition of Denise Astill for Foetal Anti-Convulsant Syndrome NZ: Changes ACC loss of potential earnings to 100% of median wage.

# We found eight emails in scope of your request

These are in the file titled *GOV-016892 attachment*. Attachments to these emails are saved as *GOV-016892 email attachments*. Some information on other petitions is out of scope and isn't being provided.

# Some of the Information is publicly available

For this reason, we are refusing to provide the following under section 18(d) of the Act. You can find them at:

- Government response to five ACC-related petitions referred to it by the Petitions Committee is publicly available here: <a href="www.parliament.nz/resource/mi-nz/resource/mi

We are withholding some information under section 9(2)(f)(iv) of the Act to protect the confidentiality of advice tendered by Ministers and officials.

Some contact details are withheld under section 9(2)(a) of the Act to protect the privacy of individuals. Staff names have not been provided as they are out of scope of the request.

We considered the public interest in releasing this information and determined that it does not outweigh the need to protect the privacy of individuals, or the confidentiality of advice tendered by Ministers and officials.

#### If you're concerned about this response, please get in touch

You can email me at <a href="mailto:GovernmentServices@acc.co.nz">GovernmentServices@acc.co.nz</a>. You can also contact the Ombudsman if you are not happy with this response via <a href="mailto:info@ombudsman.parliament.nz">info@ombudsman.parliament.nz</a> or by phoning 0800 802 602. Information about how to make a complaint is available at <a href="mailto:www.ombudsman.parliament.nz">www.ombudsman.parliament.nz</a>

Ngā mihi

Sara Freitag

**Acting Manager Official Information Act Services** 

Government Engagement & Support

Subject: FW: Ati-seizure meds dispensing data

Date: Wednesday, 24 March 2021 12:56:10 PM

Attachments: <u>image001.jpg</u> <u>image002.jpg</u>

Senior Policy Advisor – Injury Prevention, ACC

[\$ 9(2)(a) ]

ACC cares about the environment – please don't print this email

From:		@acc.co.nz>		
Sent: Wednesday, 24 Marc	th 2021 12:55 PM			
То	@acc.co.nz>;			@acc.co.nz>;
	@acc.co.nz>;		@acc.co.nz	.>
Cc:	@acc.co.r	nz>		

Subject: RE: Ati-seizure meds dispensing data

unless it is really necessary. Thank you.

Kia ora all,

I just wanted to let you know that the Ministers office has agreed for the briefing to be delayed until all data is received to allow for a fuller picture to be provided – we have tentatively agreed to 6 May as the due date.

Alongside this agreement they have asked that ACC provide Denise Astill with an update just to confirm that ACC is pulling together information for the Minister to address some of the points raised during their meeting — can I please ask someone/one of the teams who have a relationship with Denise to do this?

Otherwise I look forward to catching up with you all on next steps one we receive the Pharmac data.

Ngā mihi

```
From:

Sent: Thursday, 18 March 2021 11:12 AM

To:

acc.co.nz>;

acc.co.nz>;

acc.co.nz>;

acc.co.nz>

Subject: RE: Ati-seizure meds dispensing data
```

Kia ora and thanks

Are you comfortable with previous key advice below then, or should we add an age disclaimer?

In terms of the key advice to include to the Minister, is it:

- a. per comment, prescribing of sodium valproate for Māori females is static, despite overall in increase in prescribing across all anti-epileptic drugs, but ACC will work with its partners to monitor prescribing for Māori and Pacific females
- b. ACC will use its cross-agency meetings to raise the issue of increasing prescriptions for other anti-epileptic drugs that are likely, or have emerging evidence, to cause harm.

Please remember that we are still awaiting the PHARMAC data (under OIA so should be received in the next week or two), which often differs from the MOH data so I think we should wait for that before we reply to the Minister.

Ngā mihi



 From:
 @acc.co.nz>

 Sent: Thursday, 18 March 2021 10:08 AM
 @acc.co.nz>;

 Quacc.co.nz>;
 @acc.co.nz>;

Subject: RE: Ati-seizure meds dispensing data

This looks reassuring to me .

Most of the % prescribing is consistent with % maori female population more or less.

From which I'd infer that Maori women are not being prescribed MORE than other ethnic groups

The % maori female at ages over 65 probably tells the story of disparity ( although would need previous demographic data to confirm)

From: @acc.co.nz>
Sent: Wednesday, 17 March 2021 8:29 AM

 To:
 @acc.co.nz>;

 @acc.co.nz>;
 @acc.co.nz>

 Cc:
 @acc.co.nz>

Subject: FW: Anti-seizure meds dispensing data

Fyi, extra info re population projections from in response to the questions

Ngā mihi

(She/Her) Injury Prevention Partner, ACC

ACC cares about the environment – please don't print this email unless it is really necessary. Thank you.

From: @health.govt.nz>

Sent: Tuesday, 16 March 2021 3:26 PM
To:

@acc.co.nz>

Subject: RE: Anti-seizure meds dispensing data

Kia ora

Please find attached an updated spreadsheet that contains population projections broken down by age group and ethnicity.

In terms of the rates of diagnosed epilepsy:

A diagnosis would usually occur in a primary healthcare facility and we have no visibility of such events so do not hold this data.

We can possibly look for epilepsy hospitalisation discharges in the NMDS collection but this will likely be a severe undercount of the actual rate of epilepsy.

One possible avenue would be to contact the health survey team at healthsurvey@health.govt.nz

They have in the past complied data on epilepsy in their health survey reports.

Let me know if there is anything else that I can help you with.

Ngā mihi,

Information Analyst Data Services Ministry of Health Subject: RE: Anti-seizure meds dispensing data

Kia ora and thanks for your reply.

This is really useful information for us. It begs a couple more questions which I'm not sure you will be able to answer but I will ask them anyway:

- we do not have demographics for the age group ethnicity to refer to, so we don't know whether the percentage is about right with regard to the population at that age group
- we also don't know what the rate of diagnosed epilepsy is across ethnicity demographics. Is it the same in each group or different?

Are you able to assist with these at all?

Ngā mihi



**From:** health.govt.nz>

Sent: Monday, 15 March 2021 11:15 AM
To:

acc.co.nz>

Subject: RE: Anti-seizure meds dispensing data

Kia ora

Thanks for your reply.

Please find attached the requested data.

Note that the data is for dispensings to women only. I have broken down by ethnicity and then separately by Age group, DHB of domicile (at the time of the event), and chemical name.

Let me know if this is okay, and if you need any further data in this area please do not hesitate to let me know and I will be happy to help.

Ngā mihi,

Information Analyst Data Services Ministry of Health

From: @acc.co.nz>
Sent: Monday, 15 March 2021 6:56 am

To: <u>@acc.co.nz</u>>;

Subject: Re: Anti-seizure meds dispensing data

Kia Ora

Thanks for your email. The notes from the Minister's meeting were as follows:

There should be **more data included in the paper**, especially on rates of prescription for Māori vs non-Māori women, the geographical locations of where most prescriptions are being written and anything else that can be included that might provide a better picture of the situation and whether certain areas of the country need to be targeted in terms of education etc to try to make improvements in raising awareness of the risks. In particular, the Minister asked if we could consider accessing IDI data for this purpose, or else get it from PHARMAC/Medsafe etc.

As a result of the above, to answer your questions:

- You usually give us counts of dispensing so I presume that would be the easiest for us to do a comparison from (unless you think counts of people or quantity tells a more full picture).
- The full list of anti epilepsy meds you have included below looks good.

If you have any other information that answers the Minister's questions that would be wonderful.

Ngā mihi

Get Outlook for iOS

**From:** health.govt.nz>

Sent: Friday, March 12, 2021 12:13 PM

To:

Subject: RE: Anti-seizure meds dispensing data

Kia ora

I have extracted some data but before I go any further I wonder if you could provide some more detail on what exactly you are requiring:

Do you want counts of people, counts of dispensings, or counts of quantity? Or all three? Are there specific antiseizure medications you are looking at – I have been using those in the Therapeutic group 'Antiepilepsy Drugs' which include the following chemicals

Levetiracetam Lamotrigine Gabapentin Carbamazepine Gabapentin (Neurontin) Sodium valproate Primidone Phenytoin sodium Ethosuximide Clonazepam Clobazam Oxcarbazepine Stiripentol Phenobarbitone Diazepam Vigabatrin **Topiramate** Paraldehyde Pregabalin Phenobarbitone sodium

Are these okay?

Sulthiame Lacosamide

Finally, when you say rates do you want me to use a population denominator to calculate the rate of dispensing or can I provide raw counts?

Let me know, and feel free to ask any questions.

Ngā mihi,

From:

\_acc.co.nz>
Sent: Thursday, 4 March 2021 3:47 pm

To:
\_@health.govt.nz>;
\_@health.govt.nz>
Cc:
\_@acc.co.nz>;
\_acc.co.nz>;

Subject: Anti-seizure meds dispensing data

Kia ora

Apologies for the group email – I'm just not sure who exactly can help me with this.

Denise Astill from FACS NZ met with our Minister yesterday and we have received a number of actions as a result. One of them is about dispensing data as she was concerned about the increase in dispensing of anti-seizure meds to Maori women in 2019.

Can we please get any updated data you have on rates of prescription of anti-seizure meds (not just sodium valproate) for Māori vs non-Māori women, the geographical locations of where most prescriptions are being written and anything else that can be included that might provide a better picture of the situation to feed back to the Minister?

Please don't hesitate to come back to me with any questions

Ngā mihi



From:	@health.govt.nz>	
Sent: Thursday, 8 Oct	ober 2020 10:56 AM	
То	acc.co.nz>	
Cc:	health.govt.nz>;	<pre>ahealth.govt.nz&gt;;</pre>
	health.govt.nz>	

Subject: RE: FW: sodium valproate dhb dispensing

Hj

Nice to catch up again

My new role is working in team at the Ministry, so I was quite surprised to see your name again.

I put together this document which goes into a bit of detail about sodium valproate dispensings 2009 to 2019. I've also CC'ed in the new pharms analyst) and the whole I believe I handed your standing order to). If there's parts of this data you would want added to your standing order, that is possible to do.

Ngā mihi,

Advisor Pharmacy Ministry of Health

From: <a href="mailto:@health.govt.nz">@health.govt.nz</a>
Sent: Wednesday, 7 October 2020 8:06 am
To: <a href="mailto:health.govt.nz">health.govt.nz</a>>

**Subject:** FW: FW: sodium valproate dhb dispensing

Hi

This is the original email from wrt sodium valproate numbers.

# Ngā mihi





From: acc.co.nz>

To: health.govt.nz\*

Date: 17/08/2020 16:41

Subject: sodium valproate dhb dispensing

# Kia ora

How are you going in these crazy times? Well I hope. I hope you are enjoying your not so new role at MoH.

Can I ask a favour?

The data we received in September last year from the information you presented to the HQSC Med Safety EAG was that the top 5 DHBS re dispensing rate of valproate to women of child bearing age in 2018 was as follows:

- 1. Whanganui
- 2. Wairarapa
- 3. Hawkes Bay
- 4. West Coast
- 5. Taranaki

Given we are now a year down the line I'd really like to see if I can find out what the data for 2019 is. Can you please tell me who was able to get you the data for 2018 so I can ask them if I can have 2019 data?

Ngā mihi nui



# Injury Prevention Partner, ACC

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Subject: FW: GOV-008823 - Meeting with FACS NZ - Draft final.docx

**Date:** Friday, 26 February 2021 3:22:00 PM

Attachments: GOV-008823 - Meeting with FACS NZ - Draft final.docx

# For reading pleasure



**From:** acc.co.nz>

Sent: Friday, 26 February 2021 3:04 PM

**To:** @acc.co.nz>

Subject: Fwd: GOV-008823 - Meeting with FACS NZ - Draft final.docx

Hi

This is about LOpE is this better having you at minsters?

# Get Outlook for iOS

From:

Sent: Thursday, February 25, 2021 10:34:31 AM

To: @acc.co.nz>;

Subject: GOV-008823 - Meeting with FACS NZ - Draft final.docx

Hi

Happy for it to come from myself – just one question that I am not sure if I've read it right but I don't think it is NZs position.

Thanks

Subject: FW: LOPE and lump sum compensation petitions [IN-CONFIDENCE]

Date: Thursday, 10 September 2020 4:48:04 PM

Attachments: image001.jpg

Letter to ACC (re Petitions of Denise Astill and Jenn Hooper) 2020 08 04.pdf

Submission from Denise Astill for FACSNZ.pdf

Out of Scope

9(2)(f)(iv)

will be well-placed to assist you with this. She has already prompted our Actuaries to update the figures that were used in the LOPE briefing that went to the Minister last year (see final attachment).

Cheers





# Policy Manager, ACC

Have questions about ACC's response to COVID-19? You can find answers on our website <a href="https://www.acc.co.nz/covid-19">www.acc.co.nz/covid-19</a>?

ACC cares about the environment – please don't print this email unless it is really necessary. Thank you.

From: mbie.govt.nz>
Sent: Thursday, 10 September 2020 4:00 PM
To: @acc.co.nz>

**Subject:** LOPE and lump sum compensation petitions [IN-CONFIDENCE]

Kia ora

As discussed on Tuesday, we have received three select committee petitions – two of which concern LOPE, and one of those two also concerns lump sum compensation. The petitions are attached.

Would we be able to get some help from ACC around:

- Costings for:
  - Increasing LOPE to 100% of the minimum wage
  - Increasing LOPE to 80% of the "average" wage (which we are interpreting as the median wage)
- The current minimum and maximum lump sum compensation rates

Also happy to receive any other input you feel may be helpful.

Kia ora rawa atu,



**Graduate Policy Advisor** 

Accident Compensation Policy Team

# **Workplace Relations and Safety Policy**

Ministry of Business, Innovation & Employment

mbie.govt.nz | cid:image001.jpg@01CE732A.1A2F9630

Subject: FW: Petition referrals: five petitions relating to ACC

**Date:** Monday, 9 August 2021 2:43:54 PM

Attachments: image001.png oledata.mso

For your interest only. No action required (unless requested down the track)

Ngā mihi



ACC cares about the environment – please don't print this email unless it is really necessary. Thank you.

From: parliament.govt.nz>

Sent: Monday, 9 August 2021 2:11 PM

**To:** Government Services < <u>GovernmentServices@acc.co.nz</u>>

Cc: @acc.co.nz>

Subject: FW: Petition referrals: five petitions relating to ACC

FYI on the below.

From: dpmc.govt.nz]

Sent: Monday, 9 August 2021 2:09 PM

To: parliament.govt.nz>;

parliament.govt.nz>

Subject: FW: Petition referrals: five petitions relating to ACC

[IN-CONFIDENCE]

Hi

Please see below five petitions referred from the Petitions Committee requiring government responses to be prepared and presented to the House.

The responses will have to be approved by Cabinet. The process is set out here: Official Government response process | Department of the Prime Minister and Cabinet (DPMC)

The template for responses in the CabGuide is tailored for select committee reports (under Standing Order 256). The Standing Order reference should be amended to SO380 for petitions. Thanks,

From:	parliament.govt.nz>
<b>Sent:</b> Monday, 9 August 2021 1:39	PM
То:	dpmc.govt.nz>
Cc:	@parliament.govt.nz>
Subject: Petition referrals: five net	itions relating to ΔCC

Good afternoon

The Petitions Committee has grouped and referred the following ACC-related petitions to a Minister:

- 1. <u>Petition of Matt Davis:</u> Amendment of ACC legislation to recognise cumulative trauma <u>Request</u>: That the House of Representatives amend the Accident Compensation Act 2001 to recognise cumulative trauma as a cause of PTSD and other work place mental health injuries amongst emergency service workers and first responders.
- Petition of Denise Astill for Foetal Anti-Convulsant Syndrome NZ: Changes ACC loss of potential earnings to 100% of median wage
   Request: That the House of Representatives amend clause 47 of Schedule 1 of the Accident Compensation Act 2001 to set weekly compensation for loss of potential earnings capacity for children injured before the age of 18 years at 100% of the median wage.
- 3. Petition of Jenn Hooper MNZM: Alterations to ACC Loss of Potential Earnings (LOPE) and Lump Sum Entitlements

  Request: That the House of Representatives alter ACC's Loss of Potential Earnings (LOPE) capacity payments to 80% of average wage, and change the Lump Sum compensation levels for those with permanent injuries greater than 80% whole person impairment to better reflect the actual impairments.
- 4. <u>Petition of John Bird</u>: ACC's Behaviour toward Treatment Injury Victims, and their rights <u>Request:</u> That the House of Representatives conduct an inquiry into ACC's ethical stance, and urge the Government to instigate a reconstruction of ACC in the area of long-term treatment injury victims.
- 5. <u>Petition of Anthony Reilly</u>: Minimum ACC Payments for Victims of Treatment Injury <u>Request: That the House of Representatives amend the Accident Compensation Act 2001 to increase the minimum level of weekly compensation for victims of treatment injury, to a level that is at least equal to the adult minimum wage.</u>

Report back date: Monday, November 1, 2021.

These petitions were grouped under the Petitions Committee's power under Standing Order 378(d), to group petitions about similar topics. All of these petitions relate to ACC compensation levels and claims eligibility. As these petitions are now grouped together, only one response is

required to cover all five petitions. Please note, under Standing Order 380, the Minister's response is to be presented to the House by the report back date, and not to the Petitions Committee.

Written submissions have been received from all petitioners, and in most cases either MBIE or ACC has provided a submission. These are available under "View submissions and advice" at the above links to each petition.

Please contact me if you have any questions or concerns.

Many thanks,

Clerk of Committee (Petitions)
Select Committees and Corporate Services



Room 1.010, Parliamentary Library Private Bag 18041, Wellington 6160

s 9(2)(a) ]

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From: To: Subject: FW: Petitions - Matt Davis and Denise Astill/Jenn Hooper Date: Tuesday, 29 September 2020 10:32:16 AM Policy Manager, ACC Have questions about ACC's response to COVID-19? You can find answers on our website www.acc.co.nz/covid-ACC cares about the environment – please don't print this email unless it is really necessary. Thank you. @acc.co.nz> Sent: Tuesday, 29 September 2020 10:29 AM acc.co.nz> Subject: FW: Petitions - Matt Davis and Denise Astill/Jenn Hooper From: Sent: Tuesday, 29 September 2020 9:57 AM @acc.co.nz> Subject: FW: Petitions - Matt Davis and Denise Astill/Jenn Hooper FYI From: Education and Workforce Committee < Education. Workforce@parliament.govt.nz > **Sent:** Friday, 28 August 2020 11:49 AM To: Ministerial Servicing < Ministerial Servicing @acc.co.nz >; Education and Workforce Committee <<u>Education.Workforce@parliament.govt.nz</u>> Cc: @acc.co.nz>; @mbie.govt.nz> Subject: RE: Petitions - Matt Davis and Denise Astill/Jenn Hooper Ordinarily we would ask the committee to approve this transfer. However, given the committee now won't meet until October at the very earliest (and likely later), I think it makes sense for MBIE to work on the response and then we'll confirm this with the committee when they meet again. Let me know if you have any issues with that approach. Thanks, Clerk of the Education and Workforce & Economic Development, Science and Innovation Committees Parliament Buildings, Private Bag 18041, Wellington 6011 www.parliament.nz **From:** Ministerial Servicing [mailto:MinisterialServicing@acc.co.nz] **Sent:** Thursday, 27 August 2020 3:37 p.m. **To:** Education and Workforce Committee <<u>Education.Workforce@parliament.govt.nz</u>> Cc: acc.co.nz>; acc.co.nz>; ambie.govt.nz> Subject: Petitions - Matt Davis and Denise Astill/Jenn Hooper

I've discussed these two petitions with (Manager, Accident Compensation Policy, MBIE) and we agree that they should be transferred to MBIE as both petitions are

Hello

requesting legislative amendment. Hopefully that is OK with you?

contact details are:

mbie.govt.nz | [s 9(2)(a)]

Kind regards,

Senior Advisor, ACC

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From:

To:

Subject: FW: Petitions paper

Date: Tuesday, 28 September 2021 4:03:06 PM

Attachments: The Government response to the five ACC-related petitions referred to it by the Petitions Committee.docx

FYI

From:

**Sent:** Tuesday, 28 September 2021 3:55 PM **To:** acc.co.nz>

Subject: RE: Petitions paper

Hi

Here it is.

From:

Sent: Tuesday, 28 September 2021 2:44 pm

To: <a href="mbie.govt.nz">mbie.govt.nz</a>

Subject: Petitions paper

Hi

If possible could we please have the final version of this paper?

acc.co.nz>

Tracker Number	Title	Agency	Signed Out By	Date received
<mark>2122-0603</mark>	Response to the House on five	MBIE		24/09/2021
	petitions related to ACC			

Ngā mihi,

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From: To: Cc: Subject: FW: Petitions response including Bird [IN-CONFIDENCE: RELEASE-EXTERNAL] Date: Friday, 17 September 2021 9:58:17 AM Attachments: The Government response to the five ACC-related petitions referred to it by the Petitions Committee.docx LEG paper on government response to five ACC-related petitions.docx Kia ora Are you able to look into this for please? Ngā mihi mbie.govt.nz> Sent: Friday, 17 September 2021 9:30 AM Subject: FW: Petitions response including Bird [IN-CONFIDENCE: RELEASE-EXTERNAL] Kia ora is away today. Can you please refer this on the appropriate person? From: Sent: Friday, 17 September 2021 9:15 am @acc.co.nz **Subject:** Petitions response including Bird [IN-CONFIDENCE: RELEASE-EXTERNAL] Kia ora I have finally got the petitions response condensed sufficiently that is happy with it. You Sorry, but timing is now pretty tight so a prompt response by Monday would be appreciated. **SENIOR POLICY ADVISOR Accident Compensation Policy** Mobile:

From: To: Subject: FW: RF: Select Committee petitions Date: Monday, 24 August 2020 1:24:04 PM Attachments: Jenn Hooper - Denise Astill submission.pdf Matt Davis Submission.pdf John Bird submission.pdf Hi both. FYI, and for comment please. I'm going to send an initial response to indicating that I think MBIE should lead the response to the first (Astill/Hooper) and second (Davis) petitions, because they ask for legislative amendment. We can contribute to the response on those, including describing ACC's current approach. On the Astill/Hooper petition, ACC will need to pick up the third petition. I'll copy you into my email to et al), and please contribute any further views. Cheers Policy Manager, ACC Have questions about ACC's response to COVID-19? You can find answers on our website www.acc.co.nz/covid-ACC cares about the environment - please don't print this email unless it is really necessary. Thank you. From: @acc.co.nz> Sent: Monday, 24 August 2020 11:31 AM To: @acc.co.nz>; @acc.co.nz> Cc: @acc.co.nz>; @acc.co.nz> **Subject:** RE: Select Committee petitions and Attached are three Select Committee petitions that Ministerial Services has been asked to respond to. I have attached a brief summary of each of the petitions below. We wanted to flag these with you for your general awareness but we are also keen to get your thoughts on these, particularly the petitions from Jenn Hooper/Denise Astill and Mat Davis. The petition from Jenn Hooper may better sit with MBIE but we wanted to get your thoughts on this before discussing this with MBIE. I'm happy to hold the pen on this or to coordinate ACC's input but we thought you might have some thoughts about how to respond to this. The petition from Matt Davis will also probably need some input from legal. Summary of petitions: GOV-006210 (LOPE): Denise Astill requests changing LOPE to 100% 'median' wage -Jenn Hooper requests changing to 80% of the 'average' wage. Jenn Hooper also requests increasing the Lump Sum for those clients with over 80% impairment. On 4 June 2019, both ACC & MBIE advised the Minister



[Out of Scope]

Happy to discuss this once you've had a chance to read through these. Kind regards



#### Aide Memoire

# Meeting with Foetal Anti-Convulsant New Zealand



То	Hon Carmel Sepuloni, Minister for ACC	Priority	Medium
From	Chief Clinical Officer & Head of Health Partnerships	Reference	GOV-008823
Date	24 February 2021	Security rating	In Confidence

#### **Purpose**

- This paper provides information to support your meeting with Denise Astill, Executive Director of Foetal Anti-Convulsant Syndrome NZ (FACS NZ), on 3 March 2021.
- 2. In a briefing provided to your office by FACS NZ, Denise outlines her intention to discuss with you a range of topics relating to your portfolios as Minister for ACC and Minister for Disability Issues including:
  - Prevalence of Foetal Anti-Convulsant Syndrome (FACS)
  - · ACC current caseload
  - Current prevention strategy
  - Diagnostic pathway
  - National look-back
  - Disability packages
  - Restorative justice process
- 3. ACC understands that a separate briefing will be provided to you from the Office for Disability Issues to support your conversation with Denise.

#### **Background**

# Foetal Anti-Convulsant Syndrome NZ

- 4. Denise Astill is the mother of twin daughters with FACS and was the first to have a treatment injury claim accepted by ACC for injuries related to exposure to anti-convulsants.
- 5. Denise founded FACS NZ in February 2015 and is the Executive Director. FACS NZ is a charitable organisation that provides up-to-date information on foetal anti-convulsant syndromes, support and education to individuals and communities, and seeks to decrease the likelihood of these syndromes.
- ACC is working closely with FACSNZ to improve the experience of claimants seeking treatment injury cover for FACS-related injuries and to support injury prevention activities.

# **Foetal Anticonvulsant Syndrome**

- 7. FACS is a group of malformations that include spina bifida, cleft palate, heart defects, learning problems, and autism spectrum disorder.
- 8. Babies may be affected by malformations if they are exposed to certain medicines, known as antiepileptic drugs (AEDs), while in the womb. This occurs when AEDs taken by the mother during pregnancy cross the placenta into the developing foetus.
- 9. AEDs, such as sodium valproate, are most commonly prescribed for epilepsy but may also be prescribed for mental health issues or pain. Taking more than one AED may increase the risk of FACS.

#### ACC cover for Foetal Anti-Convulsant Syndrome

10. ACC can provide treatment injury cover for injuries suffered by children exposed in utero to anti-convulsants, if the legislation test is met. A treatment injury is a personal injury resulting from that person receiving treatment from a registered health professional.

11. In order to fulfil the criteria for cover, the client must have suffered a personal injury, there must be a clear causal link between the treatment and the injury, and the injury must not be a necessary part or ordinary consequence of the treatment.

#### New cover guidance

- 12. In July 2020, ACC published cover guidance for health professionals summarising the information ACC requires to provide cover for injuries relating to FACS caused from exposure to sodium valproate. <sup>1</sup> This incorporates a 2019 consensus statement of experts, published in an academic journal in relation to the diagnosis of FACS, <sup>2</sup> and advice from healthcare specialists who work with FACS patients and FACS NZ. The new guidance is expected to improve understanding of the ACC cover decision criteria, consistency in decision making, and claim experience.
- 13. ACC provided information to professional bodies and FACS NZ about changes in the new guidance so they may use it to support people with previously declined FACS claims on how to request for their cover decision to be reassessed.

#### Injury prevention initiatives

- 14. In 2017, ACC worked with a large group of healthcare and consumer stakeholders, including FACS NZ, to develop FACS prevention booklets for healthcare professionals and consumers.
- 15. In 2019, a similar group of stakeholders reviewed and updated the booklets and developed an injury prevention flyer. The material helps healthcare professionals discuss with patients the benefits and risks of taking anti-seizure medications during pregnancy enabling them to make an informed and consented decision. These resources are endorsed by ACC, FACS NZ, the Ministry of Health, and the Health Quality and Safety Commission, and were released in July 2020.3
- 16. ACC has also funded the rollout of the Conporto Event Detection and Mitigation system that alerts general practitioners and pharmacists to review patients who may be taking sodium valproate and who are of childbearing age. This showed an 88 percent drop in the number of female patients between 10-49 taking sodium valproate, and a 66 percent drop in the number of patients in this age group initiated onto (e.g. newly prescribed) sodium valproate between August 2018 and February 2020.
- 17. This injury prevention activity, and the declining prescribing rates, is anticipated to reduce the incidence of FACS in New Zealand-born children in the future.

#### **Claims information**

- 18. Since 2005, ACC has accepted 36 treatment injury claims (57 percent of claims received) to support babies, children, and adults affected by exposure to sodium valproate in vitro; 25 have been classified as serious injury claims. Associated costs of these claims total \$12, 654,170, to date.
- 19. In the same timeframe, ACC has declined 27 claims for sodium valproate exposure the most common reasons are that no injury was identified, or the injury was deemed an ordinary consequence of treatment.
- 20. Of the 36 accepted claims, 27 (75 percent) were for clients of European ethnicity. Clients with Māori, Pacific, or Asian ethnicities each had fewer than four accepted claims.

# Loss of Potential Earnings compensation payments

21. FACS NZ make the case that Loss of Potential Earnings (LOPE) payments are intended to substitute earnings the affected person may have made, if they were able to work. FACS NZ is therefore asking for LOPE to be raised to 100 percent of median wage, which would currently equate to \$1031.50 (gross) per week. NZ's argument is discussed further in points 31-36.

Commented

Is this NZ's argument or ACC'S?

<sup>\*</sup>Influres following in use o exposite to season to the second of the property of the statement of individuals with Foetal Valproate Spectrum Disorder; a consensus statement from the European Reference Network for Congenital Malformations and Intellectual Disability. Orphanet Journal of Rare Diseases 14, 180 (2019).

3 Foetal Anti-Convulsant Syndrome resources, <a href="https://www.tacsnz.com/resources">https://www.tacsnz.com/resources</a>. Accessed 25/02/2021

- 22. ACC provides LOPE payments to 'potential earners'. Potential earners are claimants who are injured before the age of 18 or were injured while in full-time study or training which began before the age of 18 that continued uninterrupted, until after the age of 18.
- 23. To receive LOPE payments, a claimant must be assessed as unable to perform any work to which they are suited, based on their skills. Claimants must also have been incapacitated for six months or longer.
- 24. Between the 2017 and 2020 elections, 1,111 people received a total of \$83,056,154 in LOPE payments, according to ACC data.
- 25. LOPE payments are set at 80 percent of minimum wage, or 125 percent of the supported living payment even if the claimant has been employed and earning above minimum wage since being injured.
- 26. The weekly rate for LOPE payments, as at February 2021, is \$604.80 (gross). This will increase this year, in line with increases to the minimum wage.
- 27. In Labour's 2020 Manifesto, a commitment was made to examine inequities between support through ACC, and the welfare and health systems for people with disabilities or health conditions.

#### Petitions to select committees

#### Change ACC loss of potential earnings to 100 percent of median wage

- 28. In May 2020 Denise, on behalf of FACS NZ, made a submission<sup>4</sup> to the Education and Workforce Committee asking that the House of Representatives amend clause 47 of Schedule 1 of the Accident Compensation Act 2001, to set weekly compensation for loss of potential earnings for children injured before the age of 18 years at 100 percent of the median wage. It is currently set at 80 percent of the minimum wage.
- 29. The Education and Workforce Committee requested MBIE provide a response to this petition. A copy of MBIE's response is attached at Appendix 2. Please note that this response letter is yet to be published on the Parliament website and it is unclear whether Select Committee members have reviewed the letter. This letter is therefore considered to be confidential at this time.

#### The numbers harmed by antiepileptic medicines during pregnancy

- 30. In June 2018 Denise, on behalf of FACS NZ, made a submission<sup>5</sup> to the Health Select Committee calling for a Government Inquiry into the number of babies harmed by exposure to antiepileptic medicines during pregnancy, why these occurred and are still occurring, and how to ensure informed consent.
- 31. ACC provided a submission to the Health Select Committee, on 13 July 2018.6
- 32. Prior to the Committee submitting their report in August 2020, the Committee were advised that, in the interim, Medsafe had agreed to require a pictogram pregnancy warning on the protective foil packet for Epilim (medicine used to for the treatment of epilepsy).
- 33. In March 2019, Medsafe issued a new alert announcing a change to indications and contraindications around the use of sodium valproate, also known as Epilim: it be used only to treat women with bipolar disorder as a last resort and not at all during pregnancy; only a specialist could first prescribe Epilim to a person of childbearing potential; and it be used for epilepsy during pregnancy only if there was no suitable alternative.
- 34. Denise informed the Committee she no longer required an inquiry into harm caused by antiepileptic medicines during pregnancy. Instead, she wished to see changes made to allow for prevention, diagnosis, support, and care packages.

#### **Next steps**

35. ACC officials are available to attend the meeting with Denise Astill on 3 March 2021, to support your

6 ACC submission to the Health Select Committee https://www.parliament.nz/resource/en-NZ/52SCHE\_EVI\_78066\_4737/1885/317d97165d81c83c81b08740e5561cc22d1, Accessed 25/02/21

Submission for Petition of Denise Astill for Foetal Anti-Convulsant Syndrome NZ: Changes ACC loss of potential earnings to 100% median https://www.parliament.nz/resource/en-NZ/52SCEW\_EVI\_97921\_EW8344/4099d54eae58/9146107f7122/3ec367/4134163. Accessed 25/02/
Submission for Petition of Denish Astill – Inquiry into the numbers harmed by antiepilepitic medicines during pregnancy. <a href="https://www.parliam.nz/52SCHE\_EVI\_78066">https://www.parliam.nz/52SCHE\_EVI\_78066</a> 4441/fed4800/78f63ddb929af9181db99f56ag7419e29. Accessed 25/02/2021



# **EDUCATION AND WORKFORCE COMMITTEE**

4 August 2020

Mike Tully
Chief Operating Officer
Accident Compensation Corporation

Dear Mr Tully

Petition of Denise Astill for Foetal Anti-Convulsant Syndrome NZ: Changes ACC loss of potential earnings to 100% of median wage, and Petition of Jenn Hooper MNZM: Alterations to ACC Loss of Potential Earnings (LOPE) and Lump Sum Entitlements

The above petitions are currently before the Education and Workforce Committee. Denise Astill's petition asks:

That the House of Representatives amend clause 47 of Schedule 1 of the Accident Compensation Act 2001 to set weekly compensation for loss of potential earnings capacity for children injured before the age of 18 years at 100% of the median wage.

Jenn Hooper MNZM's petition asks:

That the House of Representatives alter ACC's Loss of Potential Earnings (LOPE) capacity payments to 80% of average wage, and change the Lump Sum compensation levels for those with permanent injuries greater than 80% whole person impairment to better reflect the actual impairments.

The committee has received written evidence from the petitioners. A copy of this evidence is provided with this letter.

To assist with our consideration, the committee would like to invite ACC to provide written evidence on these petitions. As we are nearing the end of the 52<sup>nd</sup> Parliament, our Clerk of Committee will work with you to arrange a suitable date to return this evidence by.

If you wish to include any information of a sensitive nature in your written evidence, you should first discuss this with the Clerk of Committee, as the committee usually releases all evidence to the public. Please send your response to the Clerk of Committee, at ew@parliament.govt.nz.

Yours sincerely

Dr Parmjeet Parmar

Chairperson

Education and Workforce Committee