



Senator Cory Bernardi
Chairman
Finance and Public Administration Legislation Committee
Parliament House
Canberra ACT 2600

Dear Senator Bernardi,

Please find attached a copy of my letter addressed to Dr Ian Watt AO, the Secretary of the Department of Prime Minister and Cabinet, regarding evidence provided to your Committee on Friday 24 October 2014.

I request that the letter to Dr Watt AO and the attachments, be posted on the Committee's web site.

Yours faithfully

Neil D Westbury PSM
Chairperson

5 November 2014



MJD Foundation Limited

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1300-584-122

Dr Ian Watt AO,
Secretary Department of Prime Minister and Cabinet
Canberra

**Re: Evidence provided to Senate Estimates Hearings - Finance and Public Administration
Legislation Committee Friday 24 October 2014**

Dear Dr Watt,

I refer to evidence provided by officers of your department to the Senate Estimates Hearings for the aforementioned Senate Committee on 24 October 2014.

In particular, I draw your attention to the following responses to two sets of separate questions provided by officers of your department in the Hansard Proof that is now available on the Parliament's web site. The first set of questions relates to departmental responses to questions regarding a request from Ms Gayangwa Lalara, the Vice-Chairperson of the Machado Joseph Disease Foundation (MJDF), to meet and personally brief the PM regarding the impacts of Machado Joseph Disease on people in Arnhem Land, when he visited the region in September this year.

The second relates to responses by your departmental officers to questions regarding the outstanding response to a request from the MJDF on 19 February 2014 for a formal statement of reasons pursuant to the Administrative Decisions (Judicial Review) Act 1977 regarding Senator Scullion's decision to overturn a previously approved and publically announced \$10 m grant to MJDF from the Aboriginal Benefits Account (ABA).

(1) Request for Meeting with Prime Minister from MJDF

At page 18 of the Hansard Proof in relation to questions regarding the Prime Minister's recent visit to Arnhem Land, it records a question from Senator Peris and a response from one of your officers as follows.

Senator PERIS: Did the Prime Minister meet with anyone from the Machado Joseph Disease Foundation?

Ms Carroll: That organisation was invited but did not attend.

Page 52 of the Hansard Proof records the further following question from Senator Peris and response from one of your departmental officers.

Senator PERIS: Can I ask how many requests were received by the Prime Minister and the Minister for Indigenous Affairs to meet with the Machado Joseph Disease Foundation during the recent trip to Arnhem Land?

Ms Edwards: I am aware of one piece of correspondence from the MJD Foundation, but there may have been other phone calls and so on that I am not aware of.

The misleading and incomplete response of departmental officers to these questions means that the public record (as it stands) is both factually incorrect and incomplete. It would leave any one reading it to conclude that the MJDF failed to respond to an invitation to personally meet the Prime Minister, whereas in fact it was the Prime Minister's office who clearly decided he would not meet directly with the MJDF.

The facts are as follows:

The Vice-Chairperson of the MJDF Ms Gayangwa Lalara wrote to the Prime Minister on 11 July 2014 (some 9 weeks before the Prime Minister's visit) seeking a personal meeting with him when he visited Arnhem Land (see attached request).

The only response that was received occurred by means of a telephone call from one of your departmental officers on the afternoon of Sunday 14 September (just prior to the PM's arrival), advising that Ms Lalara's request for a meeting with the PM had been declined and offering instead a half hour meeting with the Assistant Minister for Health Senator Nash, on the following Wednesday 17 September.

Due to the short notice and difficulty in securing flights to Nhulunbuy Ms Lalara had to decline this invitation and a letter was sent to the PM expressing MJDF's disappointment with both the decision and the manner in which it had been conveyed.

Subsequent to this letter an email was received from your department on the 15 September further confirming a one on one meeting with the PM was not possible and canvassing Ms Lalara's potential willingness to attend a forum to be attended by a number of (unnamed) Indigenous organisations with the PM and other Minister's on Thursday 18 September, on the basis MJDF share the costs of a charter from Darwin with other organisations.

Due to the late notice, other existing commitments and the fact her request to meet and personally brief the PM regarding the impact of MJD in Arnhem Land was still being declined, Ms Lalara declined the invitation.

As it stands we understand the proposed forum did not occur, and the PM's visit to Arnhem Land was cut short and he departed on the morning of the 18th.

I would therefore request that the current deeply flawed Hansard record be corrected by the department to reflect the fact that:

- The Vice-Chair of MJDF Ms Gayangwa Lalara's written request to the PM to meet and personally brief the PM on the impacts of MJD on people resident in Arnhem Land was originally made on 11 July 2014.
- It was initially verbally responded to by a departmental officer on Sunday 14 September, both declining the requested meeting with the PM, and alternatively offering a half hour meeting with Assistant Minister Nash on 17 September in Nhulunbuy.
- A subsequent email invitation was made to Ms Lalara on 15 September to attend a forum of Indigenous organisations involving the PM and other Ministers on 18 September. Ms Lalara declined this offer as it was late notice and would still not provide her with an opportunity to personally brief the PM directly.
- As it stands the proposed forum did not occur and the PM was required to depart early.

(2) Outstanding Request For Formal Statement of Reasons

The second issue concerns responses by your departmental officers to questions regarding the outstanding response to a request from the MJDF on 19 February 2014 for a formal statement of reasons pursuant to the Administrative Decisions (Judicial Review) Act 1977 regarding Minister Scullion's decision to overturn a previously approved and publically announced \$10 m grant from the ABA to MJDF.

The relevant extract from Page 52 of Hansard is as follows.

Senator PERIS: A question for the minister; 10 months ago you overturned a \$10 million ABA grant variation for the MJDF. Has the minister responded to requests from the MJDF for a formal statement of reasons pursuant to the Administrative Decisions (Judicial Review) Act 1977?

Senator Scullion: I may need some advice from an officer about the Aboriginal Benefits Trust Account. I can attempt an answer. The Aboriginal Benefits Trust Account process is a grant process and is not subject to administrative appeal, as in some of the other decisions that are made. I would have to get some technical detail in that regard, but the other element of the question is: have we received it? We might have another officer—

Ms Edwards: We have received a request for reasons, and it is still being dealt with.

Senator PERIS: The Administrative Decisions (Judicial Review) Act is still being looked at?

Ms Carroll: The request for that review is still being considered.

The response of your departmental officers in this instance is evasive and obfuscatory and completely ignores the fact that this request was originally made on 19 February 2014 (some 10 months ago), and therefore well and truly exceeds the 28 day statutory limit. The officer's response that it is 'still being considered' falls well short of the mark in terms of providing a full and accurate response to the Senator's question.

This reflects a consistent pattern of responses from your department in relation to both this and various previous separate FOI applications made to your department and the Minister by MJDF.

In the latter case, your department's responses consistently exceeded the FOI statutory limits to such a degree that it necessitated the department reimbursing MJDF the normal fees that are payable attached to such applications.

I would therefore again request that you take action to have the Hansard record be corrected to provide an accurate reflection of the actual delay in finalising a response to the ADJR request given the extraordinary delay and clear breach of the statutory limits that apply, and the apparent total disdain for those statutory requirements by the Minister and your department.

I have also copied this letter for information to the Chair of the Finance and Public Administration Legislation Committee, Senator Bernardi and to Senator Peris.

Yours faithfully

Neil D Westbury PSM
Chairperson

5 November 2014

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1300-584-122

The Prime Minister of Australia
The Hon Tony Abbott MP

Attention: Dr Bennie Ng
Via email to bennie.ng@pm.gov.au

Re: Machado Joseph Disease in Arnhem Land

Dear Prime Minister,

I understand that you are visiting Arnhem Land country for a week in September this year. I would like to meet with you to talk to you about Machado Joseph Disease (MJD), and what this disease is doing to my people, in the country you will be staying in.

I have 6 brothers and sisters. All of them have now died from Machado Joseph Disease. On the 10th of January 2014 my sister's daughter died from MJD. She was only 44 years old, she is the first of her brothers and sisters to die so young but she has 2 brothers and a sister so far with MJD and we know that they will die very young too. There are many more in my family and in other families in communities across the NT who have MJD and who are living with dying bodies every day.

We are very worried about how MJD is damaging us now and we know that it will keep hurting us into the future. The people that are easy to see, who are already in wheelchairs, have such big problems that the services in our area cannot care for them well.

We are really worried that the people, who the government people can't see, because they are not using wheelchairs yet are not being thought about properly. We know about them because they are in our families. We know that they will get sicker and sicker and we need to help them all through their lives, not just when they are using wheelchairs.

I would like to know that you have thought about my people with this horrible problem while you are visiting our land.

I am happy to come to visit you while you are here.

You can contact our Executive Officer, Nadia Lindop on
let me know a day and time that we can meet.

or nadia.lindop@mjd.org.au to

Yours Sincerely,



Gayangwa Lalara
Vice-Chairperson
MJD Foundation

11 July 2014

MJD Foundation Limited

PO Box 414,
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The Prime Minister of Australia
The Hon Tony Abbott MP
Via Email: Meghann.everett@network.pmc.gov.au

Re: Visit to NE Arnhem Land – September 2014

Dear Prime Minister,

I refer to the phone call from your department inviting MJDF representatives to a half hour meeting with Senator Fiona Nash (Assistant Minister for Health) this Wednesday 17 September 2014 in Nhulunbuy. We understand this invitation is in response to a letter sent on 11 July 2014 (9 weeks ago) by our Vice Chairperson Gayangwa Lalara seeking a meeting with you during your current visit to Arnhem Land, for which she is yet to receive a formal response (letter attached for ease of reference).

We are extremely disappointed that you have been unable to make time in your schedule to meet with MJDF this week.

One of the early actions of your Government was to overturn the previous Government's approval of a \$10 m grant to the MJDF from the Aboriginals Benefit Account for reasons that have still not been formerly provided by Minister Scullion, consistent with the Administrative Decisions (Judicial Review) Act 1977.

Ms Lalara remains committed to meeting with you in your role as Prime Minister for Indigenous Affairs for the reasons set out in her original letter to you. Ms Lalara has lost six brothers and sisters to Machado Joseph Disease (MJD) and is very concerned to brief you personally on the realities facing individuals and families living with this terrible disease and how the MJD Foundation is working with families and governments to meet these challenges.

MJD is a genetic neurodegenerative disease. Each child of a person who carries the defective gene has a 50% chance of developing the disease. In addition, the mutation is typically expanded when it is passed to the next generation (known as an 'anticipation effect') which means that symptoms of the disease appear around 8-10 years earlier and are more severe. There is no known cure for MJD. Progression to dependence occurs over 5 to 10 years and most people are wheelchair bound and fully dependent for activities of daily living within 10-15 years of the first symptoms emerging.

The reality is that NT Indigenous Australians have the highest prevalence of MJD in the world and many individuals and families living with MJD live in NE Arnhem communities. Conservative projections confirm that up to 5% of people currently resident in a number of these remote communities have MJD and symptoms of MJD will emerge in their lifetimes.

Unfortunately because of the very short notice (phone call on Sunday 15 September) and the limited flight availability (now that Qantas has cancelled flights on this route) means we are unable to get MJDF representatives in and out of Nhulunbuy to be able to attend the allotted meeting with Assistant Minister Nash on Wednesday 17 September.

Ms Gayangwa Lalara will however be in Darwin this Thursday 18th and Friday 19th September, and would be very keen to meet with you if at all possible.

Ms Nadia Lindop will be in Canberra on Monday 20 October and would welcome the opportunity to take up Senator Nash's offer at that time. She will be available any time that day or Tuesday 21 October with the exception of Monday between 11am-12noon.



Yours sincerely,

Neil Westbury PSM
Chairperson

Email: Neil.Westbury@mjd.org.au

cc:
Gayangwa Lalara
Libby Massey

Nadia Lindop
Executive Officer

Email: Nadia.Lindop@mjd.org.au

(MJDF Vice Chairperson)
(MJDF Director, Research and Community Services)

15 September 2014

