Lueck, Christian (Health)

From: Tuck, Roger (Health)
Sent: Thursday, 19 December 2013 12:22 PM
To: Lueck, Christian (Health)
Subject: RE: Stem cell transplantation

Dear Christian,

I've had a look at the material that Colin sent and Helmut's comments. I agree with Helmut's comments, although I would ask why natalizumab is not a reasonable comparator as well as alemtuzumab.

With regard to progression of disability, 23% of the patients in the Swedish HSCT study progressed; 33% in the Canadian study which I find disappointing. The Moscow/NJ group seemed to fare much better. In the Polman trial of natalizumab vs placebo, the probability of progression was 17% in the treated group at 2 years, compared with 29% in the placebo group.

Post marketing data are also available for natalizumab; for example a Swedish group found a 2 year disease free survival (ie no relapses, no MR activity & no progression) of 84% at 2 years. In the AFFIRM trial it was only 64% (cf 39% in the placebo group). We can't directly compare these with Colin's Swedish data but their disease free survival at a mean interval of 47months was 68%; it would be helpful to see their 2 year data. If it were >90% at 47 months I'd be impressed. In that regard the Moscow/New Jersey group do claim a disease free survival rate of 92% in the group treated "early" which is impressive, but we have no direct comparison with any established treatment, and we do know that early treatment, even with interferon beta as well as alemtuzumab, seems to work better than if left until later. In support of HCST, some patients appear to improve after treatment, but that is also seen with natalizumab.

With alemtuzumab the effect on relapse rate is clear but the effect on disability progression is a bit confusing and not as impressive as one might have expected in the recent trials; in the 2012 Coles publication only 13% of alemtuzumab treated patients had progressed which looks good but surprisingly 2 year progression was only 20% in the interferon group! In the Cohen (2012) paper, there was no difference in the disability end points for alemtuzumab and interferon beta! That's why I'm not sure that alemtuzumab is a better comparator than natalizumab.

As it stands I'm not convinced yet that AHSCT is better or safer than natalizumab or (alemtuzumab) although it might be. The basic scientific reasoning seems plausible (unlike CCSVI). I have no doubt that it has a profound effect on relapse rate; and it is probably an understatement to claim that it is better than doing nothing at all (ie placebo). It has certainly become safer than it was a decade ago. Like other treatments, it might be best if used early.

As I said previously, I would consider it in a patient who has failed the best available treatment. I need to see the results of a comparative trial before I'm convinced of its wider use. The method of conditioning also needs to be settled – high, medium or low. The last of these seems to be attracting more advocates and is safer apparently. If we do offer it as an option in the light of the published material, I agree that well documented records are a must. Would we offer it as first line treatment to someone who wanted it and understood the implications?
I don't mind being involved while I'm still around if you think we should put it on the menu.

Yes, by all means tell the others of my resignation.

Roger.

From: Lueck, Christian (Health)
Sent: Tuesday, 17 December 2013 8:08 AM

To: Tuck, Roger (Health)
Subject: FW: Stem cell transplantation

Dear Roger,
See below for information, if this is any use.

One consideration from my point of view is that if we do set up a HSCT service here at TCH, I think it has to be co-ordinated by someone on the staff who should see all patients and assess them before and after against strict criteria. I think this should be the "MS neurologist". Because you are leaving, I don't think there is any point in you getting involved in beginning to set up a new service, though perhaps you could help with planning if that is the way we decide to go. It would help me very much to know where we are going but, unless you are particularly keen, I thought it might be something you could bequeath to your successor...

Incidentally, are you happy for me to let others know that you have resigned?

Best wishes, Christian

From: Lueck, Christian (Health)
Sent: Tuesday, 17 December 2013 8:03 AM
To: 'Helmut Butzkueven'
Subject: RE: Stem cell transplantation

Dear Helmut,
Thank you very much indeed for this.
That is extremely helpful.
I will keep you posted on what we decide.
Best wishes, Christian

From: Helmut Butzkueven [redacted]
Sent: Monday, 16 December 2013 5:56 PM
To: Lueck, Christian (Health)
Subject: Re: Stem cell transplantation

Dear Christian
I see this as an option with people with severe RRMS who are tysabri failures. We are trying to get approval from Box Hill Hospital Admin, where I work, to do autografts, but the process will be slow.
We would be committed to rigidly sticking to selection criteria and collecting standardised outcomes data- but not a comparative trial as there is no appropriate comparator except perhaps alumtuzumab.
I have referred one patient to Canberra , who could not be done there, and I have not yet referred any patients to sydney.
Hope this helps, I would certainly be keen for the treatment to remain available in selected centres under the conditions suggested above.
Best
Helmut

From: <Lueck>, "Christian (Health)" <Christian.Lueck@act.gov.au>
Date: Monday, 16 December 2013 12:34 PM
To: [redacted]
Subject: Stem cell transplantation

Dear Helmut,
I hope you are well.
I wonder if I could "pick your brains", please?

I received a phone call from Prof James Wiley last Thursday asking why Canberra wasn't doing stem cell transplants for patients with MS in Canberra any more. I understand from a conversation with Colin Andrews (who also wants us to get started again) that you are a proponent of HSCT and have referred patient to him (Colin) and to St.

Vincent's in Sydney. {Incidentally, please excuse me if I have misquoted anyone: my memory may be faulty!!}. In any event, I thought it might be a good idea to check with you directly.

Canberra does have the ability to perform HSCTs, but the question that has concerned the medical community here relates to whether this is appropriate treatment for patients with MS bearing in mind the potential risks involved. It was felt appropriate by several people that this treatment should be discontinued outside of the context of a controlled trial (which we don't have the capacity to run here in Canberra, incidentally). Personally, I am concerned that only two other centres in Australia are currently doing this – if it were clearly the right thing to do, why aren't more centres doing it? We don't want to disadvantage patients with MS but, equally well, we don't want Canberra to go out on a limb offering a potentially-promising but as-yet unproven therapy (which is our current take on the situation) which might ultimately prove to have been the wrong thing to do.

I am aware that promising data were presented at the most recent ECTRIMS and that the treatment is more widely used in Europe than in Australia, but could I possibly ask you for your current thoughts on HSCT to help us make a decision about what to do in Canberra? Are you in favour of this treatment being used outside a trial? If so, do you have any plans to start up a transplant service in Melbourne?

If it is easier to speak over the telephone, please feel free to ring me. My mobile is [redacted]

Thank you very much indeed for your help.
Kind regards, Christian

Lueck, Christian (Health)

From: Tuck, Roger (Health)
Sent: Monday, 16 December 2013 12:02 PM
To: Lueck, Christian (Health)
Subject: RE: Recent articles on HSCT for MS

Dear Christian,

I've had a look at some more articles as well as those that you sent me, and reviewed several that I already have. There are a few more articles that I need to track down but my view hasn't changed, at least not yet.

The published "trials" are not phase III; they are mostly phase II/"proof of concept", and do suggest that in young patients with active and possibly aggressive disease, it might be effective treatment. Whether it is more effective and at least as safe as the best that is currently available we won't know until we see the results of a comparative trial.

Mortality has dropped in the last decade from about 10% to 1-2%, but that is still a good deal higher than the mortality associated with natalizumab and alemtuzumab, quite apart from morbidity.

The page that you sent me by [redacted] is consistent with [redacted] lecture at ECTRIMS a year so ago and are probably the same data; he pointed out that about a third of patients develop progressive disability after AHCST in his series. I'll have a look for the notes that I made at the time if I can find them but I seem to recall that the median interval from HCST to onset of progression was only about 14 months (I could be misquoting him - will have to check that).

As far as I know there are 6 studies underway but not all are "controlled". One of these is a phase II trial and has been completed but not published yet. I thinks [redacted] has also been completed but not yet published; his might be controlled.

So, my view at present is that I would consider it in a young patient with active disease despite fingolimod or natalizumab (or intolerant of them) but would prefer to enrol such a case in a trial if we were part of it (which we are not). Nevertheless it's often difficult to counter the arguments of zealots in this field when they publish promising but uncontrolled data. Look at the strife associated with the much less plausible venous obstruction hypothesis!

It concerns me that such patients might in reality be difficult to treat effectively because by the time one has decided that they have failed "best available treatment" it might be too late. If we knew that HCST were the "ants pants", we might offer it first up.

Will read some more and keep you posted.

Roger.

-----Original Message-----
From: Lueck, Christian (Health)
Sent: Saturday, 14 December 2013 12:56 PM
To: Tuck, Roger (Health)
Subject: RE: Recent articles on HSCT for MS

Fantastic!
Thanks, Roger.

I had a little further pressure applied to me by Colin after the dinner on Thursday. I am not keen to start doing stem cell transplants if Canberra is one of only 3 centres in the country doing it - I really don't feel that we are "strong" enough to resist criticism if we are seen to be outliers and something goes wrong.

Having said that, I am very keen to do anything which might help patients.
Please let me know as/when you have had a chance to think about this further. I am most grateful for your help.

Best wishes, Christian

-----Original Message-----
From: Tuck, Roger (Health)
Sent: Friday, 13 December 2013 8:24 AM
To: Lueck, Christian (Health)
Subject: RE: Recent articles on HSCT for MS

Dear Christian,

I'll have a look at these articles and a broader look at the literature again. When I last reviewed the data I formed the opinion that it might have a role in early, active disease that does not respond to anything else available, and that in such (relatively rare) cases I would possibly recommend it. I also concluded that it probably is unhelpful in long standing and/or progressive MS.

Even in early onset MS, I concluded that there are no solid data comparing HSCT with the "best available" treatment (probably natalizumab or alemtuzumab), and several investigators at ECTRIMS gave me the impression that it probably has a beneficial effect on relapse frequency, but after a time, progressive disease starts in a significant percentage of cases. I think this is also what happens with mitoxantrone - it stops relapses but not progression of disability. In my view, disability is a much more relevant end point than annualised relapse rate, especially in the light of some reports that suggest that most patients recover well from most relapses, and that relapse frequency might not have much impact on the risk of long term disability, except perhaps in the first year. That was a long sentence; my former English teacher would strongly disapprove.

Until we have the results of a controlled trial (currently under way I believe in the northern hemisphere), I remain sceptical but will look at it again. Some experts think that mesenchymal stem cell transplantation is much more promising than haemopoietic cells.

I'll report back!

Roger.

-----Original Message-----
From: Lueck, Christian (Health)
Sent: Thursday, 12 December 2013 5:28 PM
To: Tuck, Roger (Health)
Subject: FW: Recent articles on HSCT for MS

Dear Roger,
I wonder if I could ask your help, please?

I have just had a phone conversation with Prof Wiley from Melbourne who called me up about the fact that we aren't performing HSCT for MS. I explained the reasons. His major concern was, apparently, the large amount of medical tourism which is going on in places like India.

He suggested that there was increasing evidence that this was a bona fide treatment arising in other parts of the world, and sent me some papers (attached).

I would very much welcome your thoughts as to whether we should be starting up a service here in Canberra or whether it is appropriate to continue to await further evidence.

Many thanks for your help.
Kind regards, Christian

-----Original Message-----
From: James Saville Wiley [redacted]
Sent: Thursday, 12 December 2013 5:20 PM
To: Lueck, Christian (Health)
Subject: Recent articles on HSCT for MS

Dear Prof Lueck,

Further to our conversation, I attach recent articles over 2011 - 2013 describing the very promising results of Haemopoietic Stem Cell Transplants (HSCT) for multiple sclerosis. Our Registry data suggests that results from follow-up of the nine patients at your hospital are at least as good as those described in these recent articles from Europe, Greece, Sweden, Canada and Russia (attached). Perhaps these new data may be relevant in future discussions with your colleagues?

With kind regards,

James Wiley

Prof James Wiley MD, FRACP, FRCPA
Chair, Registry of HSCT for MS
Florey Neuroscience Institutes,
Level 1, HFI Building
University of Melbourne
Parkville, Victoria 3010
[redacted]

Lueck, Christian (Health)

From: Tuck, Roger (Health)
Sent: Monday, 17 March 2014 10:26 PM
To: Lueck, Christian (Health); Bowden, Frank (Health)
Cc: Abhayaratna, Walter (Health); O'Donnell, Rosemary (Health); Divorty, Aimee (Health); Radcliffe, Stacee (Health)
Subject: RE: Stem Cell transplantation

Dear Christian,

A minor point that's perhaps worth noting, perhaps not! On 60 minutes Dr Federenko mentioned that he had no deaths. I can't find any refereed articles with his name but he had a poster at ECTRIMS a couple of years ago in which he stated that he had one death in a series of about 180 STCs for MS!

If he had about 10 deaths I could understand him not remembering the exact number while being interviewed by a reporter but I find it difficult to believe that he would have forgotten his one and only death; a single bad outcome always stands out.

Roger.

-----Original Message-----
From: Lueck, Christian (Health)
Sent: Friday, 14 March 2014 4:16 PM
To: Bowden, Frank (Health)
Cc: Abhayaratna, Walter (Health); O'Donnell, Rosemary (Health); Tuck, Roger (Health); Divorty, Aimee (Health); Radcliffe, Stacee (Health)
Subject: Stem Cell transplantation

Dear Frank,

I don't know whether you have seen the attached NHMRC guide to stem cell treatments - Roger just showed it to me (many thanks, Roger).

I think it is an extremely well-written guide which "60 minutes" would have done well to read before airing their program.

In particular, the paragraphs at the bottom of the two columns on the second page make for interesting reading.

Best wishes, Christian

Lueck, Christian (Health)

From: Lueck, Christian (Health)
Sent: Wednesday, 12 March 2014 12:19 PM
To: Divorty, Aimee (Health); Holmes, Pat (Health)
Cc: Radcliffe, Stacee (Health); Tuck, Roger (Health); Bowden, Frank (Health); O'Donnell, Rosemary (Health); Abhayaratna, Walter (Health)
Subject: RE: MS information - TCH treatments and MS Liaison Nurse

Thanks, Aimee.

At TCH, we provide the following for patients with MS:

- a diagnostic service, both through our general neurology clinics and via our dedicated MS clinic.
- an outpatient follow-up service
- an acute service to deal with acute relapses of MS, either through the hospital in the home or, if necessary, by admission
- advice relating to disease modifying agents which include the more longstanding treatments (the beta-interferons and glatiramer acetate) as well as more recently-introduced TGA-approved agents (such as natalizumab, fingolimod, teriflunomide and dimethyl fumarate). We regularly send clinicians to national (e.g the Australian and New Zealand Association of Neurologists) and international (e.g. the American Academy of Neurology or the European Committee for Treatment and research in Multiple Sclerosis) meetings to make sure the department is kept up-to-date and abreast of potential new MS treatments which are currently undergoing research (e.g. alemtuzumab, laquinimod, anti-LINGO, haemopoietic stem cell transplantation, EBV-specific adoptive immunotherapy, etc.) so that we are in a position to adopt them if and when they become established, evidence-based treatments.
- appropriate management of complications (spasticity and mobility issues, problems with arm function, speech and swallowing disturbance, bladder problems, depression, pain, etc.) and advice to other medical teams who are looking after patients who happen to have MS but have another, unrelated problem.

This shouldn't be looked on as an exhaustive list, but I think it gives a good overall summary.

I really don't think it would be a good idea to push the new MS nurse position too far. Pat has only started with us a few months ago so what she actually does is still in the process of development; also, she is only part-time. I think we might give the impression that we can offer more than we can if we aren't careful. Furthermore, ACT Health isn't actually funding the MS nurse, MS Australia is.

Roger, I don't know whether you will see this in time, but I wondered whether you had any comments. I am also copying this to Frank, Walter and Rosemary to make sure that they are all happy with what I have written.

Kind regards, Christian

From: Divorty, Aimee (Health)
Sent: Wednesday, 12 March 2014 11:39 AM
To: Holmes, Pat (Health)
Cc: Lueck, Christian (Health); Radcliffe, Stacee (Health)
Subject: FW: MS information - TCH treatments and MS Liaison Nurse
Importance: High

Hi Pat and Christian

I'm hoping you can assist with the below enquiry.
Could you please provide some information about the MS Liaison Nurse position and what it entails and about what MS treatments we provide at TCH?
We are hoping to include this information in a response to an urgent media enquiry from 60 Minutes.

If you could send some info to me ASAP today, I'd really appreciate it.

Thank you!

Aimee Divorty
Executive Officer
Division of Medicine
Division of Women, Youth and Children
Canberra Hospital & Health Services
Phone: 6244 3659

Care ▲ Excellence ▲ Collaboration ▲ Integrity

ACT Government Health | CANBERRA HOSPITAL AND HEALTH SERVICES

From: Smith, Josephine (Health)
Sent: Wednesday, 12 March 2014 11:11 AM
To: Divorty, Aimee (Health)
Subject: MS information - TCH treatments and MS Liaison Nurse
Importance: High

Hi Aimee,

Jess has prepared a form letter to respond to all the MS stem cell feedback we are receiving as a result of the 60 Minutes article. She has indicated that it would be a good idea to include some information around what services we do provide. To that end, could you please provide some information around the Ms Liaison Nurse and what MS treatments we provide at TCH. Jess wants Ian to clear the letter today, it would be very much appreciated if we could have this information by around 3pm.

Thanks!

Josephine Smith | A/g Business Manager
Office of the Deputy Director General
Canberra Hospital and Health Services | ACT Health Directorate | **ACT Government**
Phone (02) 6244 2169

Care ▲ Excellence ▲ Collaboration ▲ Integrity

ACT Government Health

Lueck, Christian (Health)

From: Tuck, Roger (Health)
Sent: Tuesday, 11 March 2014 11:26 AM
To: Lueck, Christian (Health)
Subject: FW: MS criteria as per our discussion

Christian,

For your info, here are the inclusion/exclusion criterea for Dr Moore's AHSCT "trial" at St Vincent's (you might already have them). It is a phase II trial; no controls. It is interesting that he is including patients with progressive disease, and with an EDSS up to 7, despite the writings of most overseas experts.

When I asked him about this he said that two patients with EDSS 7 improved to 5.5; I should have asked him for how long the improvement was sustained. I think we see a similar, transient effect of methylprednisolone sometimes in such patients although I don't think I have ever seen a patient recover quite that much (5m to 100m walking).

Seems a pity that there are no controls; similar trials have already been done but don't tell us how AHSCT compares with established treatments.

I suggested that he send this to ANZAN via [redacted]

Roger

From: John J. Moore [redacted]
Sent: Monday, 10 March 2014 4:46 PM
To: Tuck, Roger (Health)
Subject: MS criteria as per our discussion

Hi Roger – as per our discussion please find below the criteria for MS autograft as per our protocol
Thanks

1. Age 18-65
2. Adequate organ function as measured by:
    1. Cardiac LV Ejection Fraction > 45%
    2. Total Lung Capacity ³ 60%
    3. Pulmonary artery pressure < 45mmHg
    4. DLCO/VA ≥ 50%.
3. Negative serology for HBV, HCV and HIV.
4. Negative pregnancy test.
5. Able to provide informed consent and the absence of mental and cognitive deficits which can interfere with the capability of providing the informed consent.
6. Absence of severe chronic infection.
7. Severe auto-immune disease (< 7 years duration, excluding Multiple Sclerosis and CIDP) unresponsive to multiple standard therapies including corticosteroids.
8. No further feasible therapeutic options in the opinion of the referring physician.

9. Sperm collection or ova cryopreservation is to be offered prior to HSCT in those of child-bearing age.

Multiple Sclerosis (MS):

MS clinically defined and supported by laboratory tests (eg:MRI) according to MacDonald et al criteria[27]. Patients should have an EDSS between 3.5 and 7 at screening evaluation (Appendix 7) and the presence of one or more enhancing lesion on MRI. Previous Treatment with Nataluzimab is allowed *but a minimum of 3 months MUST have elapsed since completion of treatment.*

The forms of MS eligible for HSCT include:

a) Secondary Progressive form of MS with or without relapses, withrecent worsening of disease in the previous year despite immunomodulating therapy (interferon beta or glatimer acetate) and/or immunosuppressive therapy.

b) Relapsing remitting form of MS with recent worsening of disease or accumulation of disability in the previous year despite immunomodulating therapy (interferon beta or glatimer acetate) and/or immunosuppressive therapy.

c) Relapsing-remitting forms of MS who do not accumulate disability but who have at least two relapses per year, in spite of immunomodulating therapy (interferon beta or glatiramer acetate, where approved) or immunomodulating and immunosuppressive therapy and presence of one or more enhancing areas at MRI (possible repetition of MRI within three months).

d) Secondary progressive form of MS with or without relapses or relapsing-remitting MS form who accumulate disability between relapses (relapsing-progressive) with a worsening documented by EDSS during the last year in spite of the immunomodulating therapy (interferon beta or glatiramer acetate, where approved) or immunomodulating and immunosuppressive therapy, even in the absence of contrast enhancing areas at MRI.

Dr John Moore,
MB.BS, MD, FRACP, FRCPA.
Senior Lecturer, UNSW.
Senior Staff Specialist, Haematology Department
St. Vincents Hospital, NSW, 2010.
[redacted]

Lueck, Christian (Health)

From: Tuck, Roger (Health)
Sent: Thursday, 6 March 2014 8:25 AM
To: Bowden, Frank (Health)
Cc: Lueck, Christian (Health)
Subject: RE: URGNT W: 60 Minutes - Stem Cell Transplant Therapy

I've checked the AHCST trials for MS; there are currently 6 listed. Only one is randomised and controlled against current treatment (interferon beta, glatiramer acetate or mitoxantrone but apparently not against fingolimod, natalizumab or alemtuzumab – pity, perhaps they will change that) and restricts enrolment to patients with "active inflammatory disease" and EDSS 2.0-6.0, and excludes both primary and secondary progressive MS. One of the other 5 has been terminated because of low recruitment, 3 are open label, phase II and one is comparing early vs late injection of harvested stem cells. No results are available for any of these.

RT.

From: Bowden, Frank (Health)
Sent: Wednesday, 5 March 2014 7:00 PM
To: Tuck, Roger (Health)
Cc: Lueck, Christian (Health)
Subject: RE: URGNT W: 60 Minutes - Stem Cell Transplant Therapy

Roger
Thanks for your input. It confirms the information that we already have but it is good to hear it from you as well.
Frank

From: Tuck, Roger (Health)
Sent: Wednesday, 5 March 2014 6:45 PM
To: Bowden, Frank (Health)
Cc: Lueck, Christian (Health)
Subject: RE: URGNT W: 60 Minutes - Stem Cell Transplant Therapy

Dear Frank and Christian,

I'm certainly not an "expert" on MS, even less so an expert on stem cell transplantation, but here are a few points to consider....

AHSCT has been the subject of open label, phase 1 and 2 trials for MS since about 1995. No RCTs have been completed to the best of my knowledge.

The data that are available suggest that AHCST does reduce the frequency of relapses in relapsing-remitting MS (even without the benefit of controlled data), and probably decreases the risk of progression of disability, and improves disability in some cases. Nevertheless, some patients continue to have relapses and/or disease progression despite AHCST. The data suggest that the best results are obtained when patients are treated relatively soon after the onset of MS, and before secondary progression of disability begins. Mortality from ACHST has decreased in the last decade or so and depends to some extent on the nature of the "conditioning" procedure used prior to reinjection of the patient's stem cells. Mortality is probably now around 1%.

The treatments that are currently available do these things too; the newer treatments are probably more effective than interferon beta and glatiramer acetate, but are not without serious and potentially fatal side effects, and they don't always work.

My view is that in the absence of results of one or more RCTs, the only ethical way to proceed with this treatment is in the context of such a trial comparing AHSCT with the best available treatment that has been evaluated (probably natalizumab or alemtuzumab). I would consider AHSCT outside a trial in a patient who is having a lot of relapses

early in the disease who is not responding to or who can't take natalizumab, fingolimod or (when available) alemtuzumab. Such patients are uncommon.

I've left my file on this subject at home but I think the only RCT that has started or is about to start is restricting enrolment to patients who have had MS for no more than 5 years and whose disability is no more than 5.5 on the EDSS scale (able to walk without aid or rest for 100m). There might be a few more; I'll have to check.

[redacted]

I would agree with Christian's view (and that of others) that we are probably not in a position to take part in a phase III study at the moment; we are a small unit and have not even had the experience of protocol driven phase 1 or 2 trials (unless Dr Andrews patients were part of such a trial).

Call me if you would like to discuss - [redacted]

Roger

From: Bowden, Frank (Health)
Sent: Wednesday, 5 March 2014 7:47 AM
To: Lueck, Christian (Health)
Cc: Smith, Josephine (Health); O'Donnell, Rosemary (Health); Abhayaratna, Walter (Health); Tuck, Roger (Health)
Subject: Re: URGNT W: 60 Minutes - Stem Cell Transplant Therapy

Thanks Christian. Your input is very helpful.
Frank

Sent from my iPad

On 4 Mar 2014, at 11:04 pm, "Lueck, Christian (Health)" <Christian.Lueck@act.gov.au> wrote:

> Dear Josephine,
>
> I thought I should get in touch as I have been copied in to the e-mails.
> Unfortunately, I am at a conference in the US until next week and can't do much from over here.
>
> Personally, I think the media statement says it all very well. To be clear: we haven't said that the treatment is unethical. We have simply said that it would be unethical to implement it in an uncontrolled environment (hence St. Vincent's). We firmly support its introduction in a unit that has the capacity to run a controlled clinical trial. Unfortunately, this is not the Canberra Hospital. The television program doesn't quite seem to have grasped this.
>
> I think the fact almost that nowhere else in Australia is offering this treatment says a great deal about the current position among the majority of neurologists in this country. Essentially, everyone is waiting for better evidence that it is the correct management. It is rather odd that Canberra (as a rather small hospital in the scheme of things) has been singled out as a hospital that "should" be offering this treatment when almost no one else in Australia does. This is simply the result of being the closest hospital to Colin Andrews' practice, isn't it? Surely we should be supporting Colin's interest in this procedure by suggesting that he collaborate with the bigger centres (e.g. St. Vincent's or Royal Melbourne) that have the capacity to introduce this treatment in an ethical way,

not by agreeing that we should be responsible for introducing it ourselves when we don't have the resources.

I'm afraid I don't know anything about [redacted] case so can't comment.

If you need any input from the neurological side, Dr. Roger Tuck is across all the clinical information. I am copying him into this e-mail for information – Frank, Roger has looked into this issue at my request as he is officially the "MS expert" at TCH, running the MS clinic. He is very much across current evidence. Could I suggest you get in touch with him if you need any further information.

Best wishes, Christian

From: Smith, Josephine (Health)
Sent: Tuesday, 4 March 2014 6:03 PM
To: Bowden, Frank (Health); Cook, Matthew (Health); Marchesi, August (Health); O'Donnell, Rosemary (Health); Abhayaratna, Walter (Health); Lueck, Christian (Health); Lamb, Denise (Health)
Cc: Jakobs, Olivia (Health); Divorty, Aimee (Health); Pearson, Karen (Health)
Subject: FW: URGNT W: 60 Minutes - Stem Cell Transplant Therapy
Importance: High

Hi all,

Please see below email and attachments. I believe you are all across the history of this issue. I will need to talk to you all urgently in the morning about this to gather the required information to prepare a comprehensive briefing for Peggy by tomorrow evening. In particular I need information on the following:

- the chronology of events,

- The details of the ethics submission(s) and processes

[redacted]

Just to be clear, we are not answering the questions posed in the email from 60 minutes. The briefing is in preparation for when the issue hits the media.

Regards

Josephine Smith | A/g Business Manager
Office of the Deputy Director General
Canberra Hospital and Health Services| ACT Health Directorate | **ACT Government**
Phone (02) 6244 2169

Care ▲ Excellence ▲ Collaboration ▲ Integrity

<image003.png>

From: Summerrell, Jessica (Health)
Sent: Tuesday, 4 March 2014 5:10 PM
To: Smith, Josephine (Health)
Cc: Grimson, Melanie (Health)
Subject: URGNT W: 60 Minutes - Stem Cell Transplant Therapy

Hi Josephine

Please see below questions from 60 mins, which is further to the statement we provided them on Friday (attached).

I have discussed this with Peggy and she has outlined to me her recommendation regarding a response, which I will draft and send back to you for Ian's approval. However, Peggy has requested a full brief on this matter as it is clear that it is going to escalate next week – probably on Monday.

The briefing needs to cover the full background and please also make sure it includes:

- the chronology of events,
- The details of the ethics submission(s) and processes

[redacted]

I have also attached a story from SMH that was sent to us today also.

I will need this brief back by COB tomorrow (so sorry), or Thursday AM at the very latest as we will respond to 60 mins on Thursday.

FYI – Frank is across this issue from a research perspective, however the doctor campaigning is from Medicine, the other doctor involved is from Cancer.

You may also want to show Ian these additional questions as he's been intimately involved in this issue. Happy to brief you on the background over the phone.

Jess

Jessica Summerrell
A/Senior Manager
Communications and Marketing Unit
Office of the Director-General
Phone: 6205 0837
[redacted]

Care ▲ Excellence ▲ Collaboration ▲ Integrity

<image004.jpg>

From: Rice, Stephen [redacted]
Sent: Tuesday, 4 March 2014 11:46 AM
To: Whichelo, Emma (Health); Summerrell, Jessica (Health)
Subject: 60 Minutes - Stem Cell Transplant Therapy

Dear Emma and Jessica,

Thank you for the statement. However, it is very disappointing that ACT Health has declined our request for an interview. As I pointed out to you on Friday, *60 Minutes* is a television program and we operate on the basis of interviews. We do not read out press releases.

Your statement raises a number of issues. I'd be grateful if you could answer the following.

1. You say this treatment (stem cell transplant) is "not widely accepted for this use, with limited data on the efficacy and outcomes of this treatment from studies undertaken to date." Are you

aware of multiple peer-reviewed studies by Dr Richard Burt, Dr Nikolai Pfender, Dr Riccardo Saccardi and others, published in journals such as the *Lancet, JAMA* and *Current Treatment Options in Neurology*, confirming the treatment "is able to completely halt disease activity in the majority of patients"?

2. Are you aware that Dr Colin Andrews has successfully used this treatment at Canberra Hospital on at least six patients with good results in all cases?

3. Why has Canberra Hospital stopped Dr Andrews offering this procedure?

4. Does Canberra Hospital accept Dr Andrews' view that, given some people will die from the disease or be severely disabled, patients should be given the choice of giving an informed consent to such treatment? If not, why not?

5. Does Canberra Hospital accept Dr Andrews' view that most MS patients whose condition is getting worse are happy to accept the risk?

6. Does Canberra Hospital accept that the data to date shows best results in those treated early?

[redacted]

10. Was this action taken as a result of a decision by the hospital's Ethics Committee?

11. If so, how ethical is it for an Ethics Committee to start treatment and then withdraw it mid-way through such a procedure?

12. Does Canberra Hospital believe it behaved in an acceptable way and provided the best possible medical care to [redacted]?

Please respond to these issues urgently, as our report is scheduled for this Sunday night and our editing and production process will close on Thursday evening. You will note that we first requested an interview with you on this issue late last year, and again on 14 February this year, and that we did not receive a response from you until Friday evening.

Regards

Stephen Rice

Producer, *60 Minutes*

 **NINE NETWORK AUSTRALIA**
24 Artarmon Road (PO Box 27) Willoughby NSW 2068 Australia
[redacted]
http://sixtyminutes.ninemsn.com.au

Lueck, Christian (Health)

From: Dr Colin Andrews [redacted]
Sent: Thursday, 5 March 2015 2:36 PM
To: Pidcock, Michael (Health)
Cc: Lueck, Christian (Health); James Wiley; Palfreyman, Emma (Health)
Subject: Recent Long-term Results from the Moscow Group

Dear Michael,

Currently I have had patients who have been to Moscow and have returned after having autologous hematopoietic stem cell transplantation and also have many patients who are booked in for Moscow, now out to at least two years.

The patients are earlier and less severe cases with MS that have been going to Moscow and this is the group I think in future we should be targeting as the results are going to be better and less risk involved.

The cumulative incidence of disease progression is 16.7% at 8 years and is certainly much better than the earlier studies but I think this all comes down to selection which is what Dr Burt is advocating.

Below is a link to the most recent study from the Moscow group of 99 patients with long-term follow up presented in February this year.

http://www.ncbi.nlm.nih.gov/pubmed/25711670

Given that the options for secondary progressive MS are very limited, probably mitoxantrone and rituximab being the only agents that have shown any promise in that area given that Tysabri, alemtuzumab and Gilenya are without any scientific evidence of efficacy it leaves autologous bone marrow transplantation as a very viable third-line option.

I think another approach to the Ethics Committee using the St Vincent's protocol should be pursued again.

Regards
Colin Andrews

Lueck, Christian

To: Bertram, Sophie

Cc: O'Donnell, Rosemary; Buchanan-Grey, Marina; D'Rozario, James

Subject: RE: DLO12/139 - Constituent Call - complaint regarding treatment put on hold for Multiple Sclerosis [redacted]

Dear Sophie,
Many thanks.

[redacted]

Kind regards, Christian.

From: Bertram, Sophie
Sent: Monday, 25 June 2012 3:58 PM
To: Lueck, Christian
Cc: O'Donnell, Rosemary; Buchanan-Grey, Marina
Subject: FW: DLO12/139 - Constituent Call - complaint regarding treatment put on hold for Multiple Sclerosis - [redacted]

[redacted]

Thank you
Regards

Sophie Bertram
A/G Executive Officer
Division of Medicine
Division of Women, Youth and Children
Canberra Hospital & Health Services
Phone: 6244 3659

Care ▲ Excellence ▲ Collaboration ▲ Integrity

ACT Government Health | CANBERRA HOSPITAL AND HEALTH SERVICES

From: Corey, Janelle
Sent: Monday, 25 June 2012 2:56 PM
To: Bertram, Sophie
Cc: O'Donnell, Rosemary; Andersen, Jackie; Wheatley, Janelle
Subject: FW: DLO12/139 - Constituent Call - complaint regarding treatment put on hold for Multiple Sclerosis - [redacted]

[redacted]

As usual can you please provide feedback?

Cheers,

Janelle Corey
Executive Officer
Office of the Deputy Director General, Canberra Hospital & Health Services
Phone: 6244 2169
[redacted]

Care | Excellence | Collaboration | Integrity

ACT Government Health | CANBERRA HOSPITAL AND HEALTH SERVICES

From: Andersen, Jackie
Sent: Monday, 25 June 2012 2:36 PM
To: Corey, Janelle
Cc: Wheatley, Janelle
Subject: DLO12/139 - Constituent Call - complaint regarding treatment put on hold for Multiple Sclerosis - [redacted]

Hi Janelle

[redacted]

Regards

Jackie Andersen | Directorate Liaison Officer

Health Directorate | ACT Government
Phone: 6205 0499 | Fax: 6205 3030 | Email: jackie.andersen@act.gov.au

Lueck, Christian

From: D'Rozario, James
Sent: Thursday, 7 June 2012 6:20 PM
To: Lueck, Christian
Subject: Issues with MS patients being referred for Autologous transplantation

Christian,

I'm sure youre aware of various issues in the last year or so with patients with MS having been referred to one Haematologist for autografting in a rather ad hoc manner As the actual Director of the Stem cell transplant unit at this hospital, this concerns me greatly and various attempts that have been made to bring some sanity to the situation have been thwarted by the continued activity of 2 clinicians in particular.

There are many issues surrounding this but one of the more difficult ones is the " politicization" of the treatment with vulnerable, emotionally driven patients being offered a service with vague, ill defined or at some points, non existent clinical pathways. 50% of the patients seem so far with MS in our unit are from interstate and essentially self referred (faclitated by a local Neurologist whom I think you know has been involved). The first patient in 2009 was given I think ill conceived media coverage which only served to bring about greater problems. Last week a MS patient made overtures to the Chief Minister having been disappointed that her transplant is not immediately going ahead because of " ethical concerns" - I've been advocating a formal study to be approved by HREC with a defined protocol and multi disciplinary care.

A year ago - in an attempt to bring some sanity to the situation, I proposed looking at doing this form of controlled study/ registry of MS patients undergoing transplantation after doing an exhaustive review of the world literature and BMT registry data to date. A draft protocol is in development and we've since contacted a couple of other centres in Australia whove done some transplantation for this indication in Perth and St Vs Sydney. A teleconference was held last week and we are proposing collaborating with the interstate sites in setting up standard protocols and referral pathways as well as mutli disciplinary post transplant care pathways.
The MS society is aware of these developments and were represented at the teleconference last week

I would concede that the treatment may have some benefit in selected patients with MS but don't feel the way it's been gone about in Canberra is appropriate. A properly conducted study with involvement of those with necessary expertise is what I think is needed rather than the ad hoc way things have been done so far. I don't feel the 2 clinicians driving things at present are equipped to take the more sophisticated approach embodied by a formal study and would very much like to discuss the proposal with you and the other Neurologists - preferably over a cup of coffee. With patients now approaching the Chief Minister, one response for the rest of us would be to defuse the grandstanding of some and try and explore the feasibility of a rigourous evaluation of the modalitie's efficacy

James

Lueck, Christian (Health)

To: Bowden, Frank (Health)
Cc: O'Donnell, Rosemary (Health); Abhayaratna, Walter (Health); Tuck, Roger (Health)
Subject: Colin Andrews etc.

Dear Frank,
I am very sorry to hear that this issue hasn't gone away.
I have been thinking about a possible statement and would offer the following for consideration. Please feel free to check with all parties and modify it as you see fit. I have written it as though it comes from the Hospital: on reflection, this seems a bit more appropriate than singling out the neurology department as we don't actually administer the treatment.
Please get back to me as/when I can help further.
Best wishes, Christian

"The question of whether Canberra Hospital offers human stem cell transplantation (HSCT) for patients with multiple sclerosis (MS) is not one of economics. Rather, it is one of offering our patients the best possible treatment based on evidence, not anecdote. HSCT is an, as yet, unproven treatment for MS with an unacceptably high risk of complications, including death. Although we believe that HSCT may in the future be shown to benefit a small group of carefully-selected patients, there is currently insufficient evidence to support its use. Studies are currently underway in other parts of the world to determine whether HSCT is beneficial in MS and, if so, to whom. Responsible medical care requires that we do not offer a treatment with unacceptably high risk to *any* individual until we know that the treatment is scientifically and ethically sound and we can determine which patients are likely to benefit from it. This is not currently the case."

[Also, you might want to refer them to the NHMRC document on stem cell treatment.]

Lueck, Christian (Health)

To: Pranavan, Gane (Health); Lahoria, Rajat (Health)
Subject: Mitoxantrone

Dear Pranavan and Rajat,

Many thanks for meeting today. I hope we have come up with a workable and politically-acceptable solution.

Could I suggest that you and the other oncologists consider writing a letter to all neurologists in Canberra? The neurologists currently are:

Prof. Christian Lueck
Dr. Andrew Hughes
Dr. Chandi Das
Dr. Craig McColl (Calvary and TCH)
Dr. Ram Malhotra (Private and TCH VMO)
Dr. Rajat Lahoria
Dr. Colin Andrews (Private)
Dr. Yash Gawarikar (Calvary)
Dr. Ramesh Sahathevan (Calvary)
(Dr. Omar Ahmad – comes down from Sydney to do a clinic every two months, about to stop)*
(Dr. Kate Ahmad – comes down from Sydney to do a clinic every two months, about to stop)*

*You might not feel it worth writing to Omar and Kate as they are trying to stop visiting Canberra – too much work in Sydney!

I have drafted a suggested text below. Please feel free to modify it as you think fit.

Kind regards, Christian

Dear [Neurologist],

The oncology department at the Canberra Hospital has started to receive an increased number of referrals for mitozantrone in patients with multiple sclerosis. As I am sure you can appreciate, the department is under increasing pressure and so accommodating these requests is becoming more difficult. In addition, we have a number of concerns in relation to indication and, more importantly, safety. We have discussed the issue with the neurology department and would make the following points:

1. We do not consider it to be good clinical practice to administer a cytotoxic drug with potential significant side-effects to patients living outside the ACT and immediately-surrounding NSW as we are not in a position to follow them up and deal with any adverse effects which might occur. If the treatment is appropriate, it should be organised locally.
2. Similarly, we feel that treating patients who have already had a bone marrow transplant with mitoxantrone is potentially harmful and would not be prepared to offer mitoxantrone to such patients without evidence from clinical trials that it is safe.
3. We are not aware of any convincing evidence that mitoxantrone is beneficial to patients with secondary progressive multiple sclerosis.
4. We do understand that mitoxantrone is potentially appropriate in the treatment of MS patients with highly active relapsing and remitting disease who have failed other treatments.

We thought it would be helpful to let you know the situation from our point of view. If you have a patient with active relapsing and remitting disease who has failed other therapies, we would be more than happy help if we can.

However, we feel it is not appropriate to offer mitoxantrone to patients who do not fit this particular indication or to those who live outside our immediate catchment area.

We apologise for any inconvenience this might cause but trust you will understand.

Yours, etc. etc.

DR. COLIN J. ANDREWS
MB BS (SYD) MD (UNSW) FRACP
Consultant Neurologist

Provider Number: 0006561W

Suite A8, Canberra Specialist Centre
161 Strickland Crescent
Deakin ACT 2600

Ph: (02) 6282 4807 Fx: (02) 6285 3609

13 December 2013

Prof Christian Lueck
The Canberra Hospital - Neurology
PO Box 11
WODEN ACT 2606

Fax: 6244 4629

Dear Christian,

RE: **Autologous Haematopoietic Stem Cell Transplantation for Aggressive Multiple Sclerosis**

Further to our discussion last night, 12/12/12013, I enclose some up-to-date studies that you may not be aware of. There are two posters of studies presented at ECTRIMS in Copenhagen in October and a study in experimental haematology from the Moscow Group which I think is excellent.

The Swedish methodology and the Moscow methodology fairly well mirrors what we are doing and is the main method used in Europe.

There are different intensity treatments. The ATG and BEAM is regarded as mid range.

I would be grateful if you could talk to Roger and the Director of Haematology with regards to our current problems.

Currently patients are having to go overseas to have this treatment. I have fortunately been able to have a few patient done at St Vincent's in Sydney by John Moore and there are a few more in the pipeline, but he is now starting to become somewhat booked out and I think it is fairly important that the Canberra group try to resume this if at all possible.

With kind regards,
Yours sincerely,

Dr Colin J Andrews

Cc Dr Michael Pidcock
Prof J Wylie, Chairman Stem Cell Research Group
[redacted]

Haematopoietic stem cell transplantation for multiple sclerosis: the Swedish experience

Introduction: Hematopoietic stem cell transplantation (HSCT) has been performed for multiple sclerosis (MS) since 1995. The goal of this therapy is to achieve long-term remission through short-lasting ablation of the immune system. Initially, patients with treatment-resistant progressive forms of MS were treated, largely with disappointing results. Eventually, HSCT was tried for relapsing-remitting MS (RRMS) and today an emerging corpus of evidence suggests that HSCT can be a very effective therapy for RRMS. In Sweden, HSCT has been used as a rescue therapy for aggressive MS since 2004. In this study we describe the outcome of the Swedish patients.

Materials and methods: We identified a total of 48 patients who had been treated with HSCT for MS up until February 2013. A vast majority of patients were relapsing remitting (83 %); mean age was 31 years (±8.3 years); mean disease duration before HSCT was 75 months (±62 months); mean annualized relapse rate in the year preceding HSCT was 4.1 (±3.8); 41 patients were treated with a medium intensity protocol (BEAM + ATG) and 7 patients were treated with a low intensity protocol (cyclophosphamide + ATG).

Results: Patients with at least one year of follow up (n=41) were analysed further. The mean follow-up time was 47 months (±29 months, range 12-108). Relapse free survival was 89 %; MRI event free survival was 88 %; expanded disability status scale (EDSS) score progression free survival was 77 %; event free survival (no relapses, no new MRI lesions and no EDSS progression) was 68 %.

Presence of gadolinium enhancing lesions prior to HSCT was associated with a favorable outcome (event free survival 79 % vs 46 %, p=0.028). Other factors such as relapsing-remitting disease course, age, disease duration and EDSS were investigated but no statistically significant differences could be demonstrated.

Overall mortality was 0 %. Apart from the expected side effects of sepsis and culture negative fever in connection to the procedure, 7 patients (15 %) experienced Herpes Zoster reactivation; 4 patients developed thyroid disease (8.3 %); one patient developed Crohn's disease; one patient developed alopecia areata; and one patient contracted epilepsy.

Conclusion: HSCT is an effective treatment of MS, with a high proportion of patients being free from disease activity. Patients with inflammatory disease activity prior to treatment are more likely to respond to the procedure. HSCT can be performed relatively safely at experienced centres.

543

0262853609

Long-term outcome of the Canadian multiple sclerosis BMT study: efficacy and safety of treating aggressive multiple sclerosis with immunoablation and autologous stem cell transplantation

Immunoablation followed by autologous stem cell transplant(ASCT)has been studied as a potential treatment for MS. This study examined whether a long-lasting MS progression free response is induced for patients with active and progressive disease who are predicted to have a poor prognosis. The Canadian MS/BMT trial is a non-randomized phase II trial of intensive chemotherapy and CD34 selected ASCT in 24 patients considered at high risk of progression with aggressive MS who failed ≥1year of standard treatment with and EDSS≥3 and ≤6. Patients underwent stem cell mobilization following high dose cyclophosphamide(CTX)and G-CSF. Immunoablation with CTX,anti-thymocyte globulin(ATG)and adjusted-dose busulphan was followed by infusion of an ASCT graft depleted of immune cells. Patients were closely followed every 3 months for 3 years and then every 6 months, for up to 10 years with regular clinical visits, MRI's, immunological, neuropsychological and CSF assessments. None of the patients received disease modifying medication after the ASCT.

The first transplant occurred in October 2001 and the 24th in December 2009. The median follow-up of the group was 68 months. Serious toxicity developed in 2 patients receiving the highest dose of oral busulphan leading to a transient capillary leak syndrome in one and fatal liver necrosis in the other. After 1700 patient-months of follow-up, not a single patient experienced any further signs of inflammatory disease activity. The EDSS stabilized or improved in 15 patients while 8 patients experienced sustained EDSS progression in the absence of inflammatory activity. Late ASCT complications included premature ovarian failure (n=14),varicella zoster reactivation (n=7) and hypothyroidism (n=5). An initial increase in the rate of brain volume loss related to the acute effects of chemotherapy was followed by a return of the rate of loss of brain tissue comparable to reports for unaffected controls. These results demonstrate that rigorous treatment designed to ablate the auto-destructive immune system of patients with MS results in complete and long-term cessation of detectable CNS inflammatory activity without the need for chronic immunosuppressive therapy following the reestablishment of a protective and tolerant immune system. While some patients continued to show progression even in the absence of overt inflammatory activity, the disabilities in the majority of patients stabilized or improved. This is the first treatment ever shown to reverse brain atrophy in MS.

ELSEVIER

Experimental Hematology

Experimental Hematology 2012;40:892–898

Autologous hematopoietic stem cell transplantation with reduced-intensity conditioning in multiple sclerosis

Jury L. Shevchenko[a], Alexey N. Kuznetsov[a], Tatyana I. Ionova[a], Vladimir Y. Melnichenko[a], Denis A. Fedorenko[a], Andrei V. Kartashov[a], Kira A. Kurbatova[a], Gary I. Gorodokin[b], and Andrei A. Novik[a]

[a]*Pirogov National Medical Surgical Center, the Department of Haematology and Cellular Therapy and the Department of Neurology, Moscow, Russia;* [b]*Health Outcomes Department, New Jersey Center for Quality of Life and Health Outcomes Research, Saddle River, NJ, USA*

(Received 6 April 2012; revised 25 June 2012; accepted 27 June 2012)

High-dose immunosuppressive therapy with autologous hematopoietic stem cell transplantation (AHSCT) is a new and promising approach to multiple sclerosis (MS) treatment. In this article, we present the results of a prospective phase II open-label single-center study with the analysis of the safety and efficacy of high-dose immunosuppressive therapy+AHSCT with reduced-intensity conditioning regimen in 95 patients with different types of MS. The patients underwent early, conventional, and salvage/late transplantation. Efficacy was evaluated based on clinical and quality of life outcomes. No transplantation-related deaths were observed. The mobilization and transplantation procedures were well tolerated. All the patients, except one, responded to the treatment. At long-term follow-up (mean 46 months), the overall clinical response in terms of disease improvement or stabilization was 80%. The estimated progression-free survival at 5 years was 92% in the group after early AHSCT vs 73% in the group after conventional/salvage AHSCT. Statistically significant difference between the survival probabilities of two groups was determined ($p = 0.01$). No active, new, or enlarging lesions in magnetic resonance imaging were registered in patients without disease progression. All patients who did not have disease progression were off therapy throughout the post-transplantation period. AHSCT was accompanied by a significant improvement in patient's quality of life with statistically significant changes in the majority of quality of life parameters ($p < 0.05$). The results of our study support the feasibility of AHSCT with reduced-intensity conditioning in MS patients. Multicenter cooperative studies are needed for better assessment of treatment results and optimization of the treatment protocol of AHSCT with reduced-intensity conditioning regimens in MS. © 2012 ISEH - Society for Hematology and Stem Cells. Published by Elsevier Inc.

Multiple sclerosis (MS) is one of the most common neurological disorders; it mainly affects young adults and causes a gradual decrease in their quality of life (QoL). MS progression inevitably leads to the loss of motor function, sensitive disturbances, and cognitive impairment because of the immune-mediated demyelination and axon degeneration [1]. Ten years after onset about 50% of patients have a chronic progressive course [2,3], with this proportion increasing to 70% after 15 years from disease onset and to 85% after 25 years [4]. MS is a chronic inflammatory disorder of the central nervous system (CNS) caused by an autoimmune reactivity of T cells toward CNS myelin components [4]. Conventional disease-modifying treatments do not provide satisfactory control of MS due to their inability to eradicate the self-specific T-cell clones. Immunosuppressive treatments, which are frequently used as second-line therapy, also have only partial beneficial effects [4,5].

Recently, high-dose immunosuppressive therapy (HDIT)+autologous hematopoietic stem cell transplantation (AHSCT) were proposed as a new and promising therapy for MS patients [6–8]. By now, centers in Europe, North and South America, Russia, China, Israel, and Australia have the experience in using HDIT+AHSCT for MS treatment. Since 1995, several clinical studies have addressed the issue of feasibility and efficacy of HDIT+AHSCT in MS and a certain clinical benefit has been shown [9–14]. The rationale of this method is that ablation of aberrant immune system followed by reconstitution of the new immune system from hematopoietic stem

Offprint requests to: Tatyana I. Ionova, Ph.D., Department of Haematology and Cellular Therapy, Pirogov National Medical Surgical Centre, 70 Nizhnaya Pervomaiskaya str., 105 207 Moscow, Russia; E-mail: tation16@gmail.com

0301-472X/$ - see front matter.
http://dx.doi.org/10.1016/j.exphem.2012.07.003

cells may alter the characteristics of the T-cell responses and other immunological properties that might improve the clinical course of MS. At the same time, despite the promising clinical results, there are still several questions to be clarified before recommending HDIT+AHSCT as a treatment choice for MS patients.

One of the key issues is the selection of a conditioning regimen. In the neurological community worldwide, there are concerns that HDIT+AHSCT is accompanied by an increased risk of mortality and adverse effects. Major results of clinical studies with different intensity conditioning used in MS patients are [9,14–20] shown in Table 1.

In the recent Guidelines of European Group for Blood and Marrow Transplantation for HSCT in severe autoimmune diseases the risk-to-benefit ratio is defined as a major issue for such a treatment [21]. Transplantation-related mortality during the recent years is slightly above 1% [22]. The analysis of the data in the Autoimmune Disease Working Party registry of the European Group for Blood and Marrow Transplantation (EBMT) has shown that intensive HDIT regimens have been associated with increased toxicity, including transplant-related mortality [23,24]. Therefore, the rationale of evolution from myeloablative to nonmyeloablative transplant regimens has been discussed recently [25]. At present, BEAM as the conditioning regimen is the most frequently used in MS patients [7,12,13,17,26–30]. There are also low-intensity regimens: cyclophosphamide (CY) alone, melphalan alone, and fludarabine-based regimens [31]. It was shown that the CY/rabbit anti-thymocyte globulin (ATG) regimen is associated with similar outcome results, but presented less toxicity when compared with the BEAM/horse ATG regimen [19]. The rational to use less intensive conditioning regimens is supported by the suggestion that AHSCT is not only an immunosuppressive therapy, but also could have an immunomodulatory component [32]. Taking into account that a moderate intensity and less toxic regimen could induce durable long-term remission, comparable with the high-intensity regimens, but without being associated with the higher transplant-related mortality characteristic of high-intensity regimens, we aimed to study if the reduced-intensity regimens based on BEAM are safe and effective in MS patients. At the same time, there is evidence that the intensity of conditioning may be associated with a sustained long-term response and control of disease activity [33]. Thus, we provided a long-term post-transplant follow-up of our population of MS patients.

In addition, comprehensive evaluation of treatment outcomes after HDIT+AHSCT is very important. For MS patients, both disease-free period and improvement of patient's QoL are recognized as important outcome parameters. With this in mind, in our study we aimed to evaluate both clinical and patient-reported outcomes after HDIT+AHSCT.

We report the results of a prospective phase II open-label single-center study with the analysis of the safety and efficacy of HDIT+AHSCT with reduced-intensity conditioning in 95 patients with different types and stages of MS.

Patients and methods

Ninety-five patients with MS: secondary progressive MS (SPMS), 35 patients; primary progressive MS (PPMS), 15 patients; progressive-relapsing MS (PRMS), 3 patients; and relapsing-remitting (RRMS), 42 patients (mean age 34.5 years; male/female, 36/59) underwent HDIT+ASCT in the Transplantation Unit, Department of Haematology and Cellular Therapy, National Medical Surgical Centre in Moscow from July 2006 to January 2011. The study was conducted according to the

Table 1. Clinical studies of multiple sclerosis treatment with different intensity conditioning followed by AHSCT

First author of study	No. of patients	Conditioning	Conditioning intensity grade	Progression-free survival	Treatment-related mortality (%)
Nash [14]	26	CY 120 mg/kg/TBI 800 cGy/ATG	High	76% at 40 months	3.8
Burt [9]	21	CY 120 mg/kg/TBI 1200 cGy	High	62% at 24 months	9.5
Freedman [15]	15	BU 9-16 mg/kg/CY 200 mg/kg/ATG	High	60% at 60 months	6.6
Saccardi [16]	178	BEAM/ATG (41%) BEAM (17%) BCNU/CY/ATG (11%) CY/TBI/ATG (9%) BU/ATG (6%) Others (11%) Unknown (5%)	High/intermediate	63% at 42 months	5.3
Ni [17]	21	CY 120 mg/kg/TBI 1000 cGy/ATG (5%) BEAM/ATG (95%)	High/intermediate	75% at 42 months	9.5
Krasulova [18]	33	BEAM/ATG or in vitro purged graft	Intermediate	64.3% at 5 years	0
Hamerschlak [19]	21	BEAM/ATG	Intermediate	47.6% at 3 years	7.5
Burt [20]	21	CY 200 mg/kg/ATG	Low	100% at 37 months	0
Hamerschlak [19]	20	CY 200 mg/kg/ATG	Low	70% at 2 years	0

TBI = total body irradiation.

principles of the Helsinki Declaration, and was approved by the Institute Research Board and local Ethics Committee before initiation. All patients gave written informed consent. Patients were eligible if they were aged between 18 and 55 years and met the McDonald criteria for clinically definite MS [34]. Other criteria for patient selection were Expanded Disability Status Scale (EDSS) score 1.5 to 8.0 (median EDSS at baseline was 3.5), normal mental status, and absence of severe concomitant diseases. The vast majority of patients were refractory to conventional therapy, which included interferon-beta, copaxone, and mitoxantrone, as well as steroids, azathioprine, intravenous immunoglobulin, and plasmapheresis in some patients. Forty-two patients underwent early (EDSS 1.5–3.0, patients soon after diagnosis in case of primary refractory disease or poor prognosis), 50 patients underwent conventional (EDSS 3.5–6.5, patients with secondary refractory disease), and 3 patients underwent salvage (EDSS 7.0–8.0, patients with high disease activity and rapid neurological deterioration in late stages of the disease) transplantation in accordance with the concept of HDIT+ASCT in MS [29]. The mean follow-up was 46 (range, 10–66) months.

Neurological assessment using EDSS was performed at baseline, at discharge, at 3, 6, 9, and 12 months after transplantation, every 6 months thereafter up to 48 months, and then at yearly intervals. Magnetic resonance imaging scans of the brain and cervical spinal cord with gadolinium enhancement were performed at baseline, at 3, 6, 9, and 12 months after transplantation, every 6 months thereafter up to 48 months, and then at yearly intervals. QoL was evaluated using RAND SF-36 questionnaire [35].

Hematopoietic stem cells were mobilized with granulocyte colony-stimulating factor at 10 μg/kg according to EBMT/European League Against Rheumatism guidelines. The mobilized cells were collected by apheresis, until a yield of at least 2×10^6 per kg $CD34^+$ cells was obtained. The grafts were not manipulated. Reduced-intensity conditioning regimen based on BEAM, i.e., low-intensity conditioning [31] was used. It included BCNU/CCNU 300 mg/m^2 and melphalan 50–100 mg/m^2 (BM) or BCNU/CCNU 300 mg/m^2, etoposide 75–100 mg/m^2, Ara-C 75–100 mg/m^2 and melphalan 50–100 mg/m^2 (mini BEAM-like). Sixty patients were conditioned with BM, others with mini BEAM-like. Conditioning was followed by AHSCT (day 0) ±horse ATG (ATGAM, Pharmacia & Upjohn Company, Peapack, NJ, USA) in a dose of 30 mg/kg on days 1 and 2 for in vivo T cell-depletion. Five micrograms per kilogram subcutaneous granulocyte colony-stimulating factor were administered from day 5 post-infusion until granulocyte recovery. For infection prophylaxis, oral ciprofloxacin and fluconazole were used.

Toxicity was evaluated in accordance with the National Cancer Institute Common Toxicity Criteria, version 2. Neutrophil engraftment was defined as the first day after transplantation when the absolute neutrophil count was >500 cells/mL. Platelet engraftment was defined as the first day after transplantation when the platelet count was >20,000 platelets/mL without platelet transfusion.

According to the EBMT criteria of response, patients with either steady EDSS scores representing a halt of disease progression or with improved EDSS scores, representing cessation of inflammation in the CNS, were regarded as responding to treatment [7]. Improvement in neurological function was defined as a decrease in the EDSS score of at least 0.5 points on two consecutive visits 3 months apart as compared with the baseline. For RRMS, a decrease in the number of relapses per year was defined as a clinical improvement. Disease progression was defined as an increase in the EDSS score of 0.5 points or more on a minimum of two occasions that were at least 3 months apart. For RRMS disease progression was defined as an increase in number of relapses per year. A relapse of MS was defined as an acute deterioration in neurological function that lasted for more than 24 hours without intercurrent illness or another cause for neurological impairment and with objective changes on neurological examination.

Transplantation-related mortality definition included every death occurring within 100 days of transplantation [12,13]. Progression-free survival was calculated using the Kaplan-Meier method. QoL data were analyzed using the Friedman repeated measure analysis of variance on ranks.

Treatment outcomes are reported as of November 2011, based on the last follow-up of each patient.

Results

Safety

No transplantation-related deaths were reported among the 95 MS patients, irrespective of their clinical condition at the time of transplantation. In addition, there were no deaths in the study throughout the follow-up period. The mobilization and transplantation procedures were well tolerated. Mobilization was successful in all cases. There were no nonhematological toxicities of grade III severity or greater during transplantation. Common adverse effects after the HDIT+AHSCT were thrombocytopenia (100%), neutropenia (100%), fatigue (100%), anemia (80%), alopecia (80%), neutropenic fever (31,6%), hepatic toxicity grade I and II (42,1%), transient neurological dysfunction (27,4%), enteropathy (7,4%), skin allergy (8,4%), pneumonia in 2 patients (2.1%), oral candidiasis in 1 patient (1.05%), nasal hemorrhage in 1 patient (1.05%), uterine bleeding in 2 patients (2.1%), oral herpes in 1 patient (1.05%), and genital herpes in 1 patient (1.05%). Documented sepsis was registered in three patients (3.2%) on day 7 and day 10 after transplantation. The first patient had severe sepsis and septic shock caused by *Enterococcus faecium* associated with pneumonia and enteropathy on day 7 after transplantation. Sepsis was successfully treated in the intensive care unit. The second patient had enteropathy, sepsis, and cytomegalovirus colitis with recurrent rectal bleeding on day 7 after transplantation. Sepsis and rectal bleeding were successfully treated in the intensive care unit. The third patient had systemic inflammatory response syndrome on day 10 after transplantation with febrile fever, tachycardia, and procalcitonin test >2, without positive blood culture. The patient was successfully treated by meropenem and vancomycin for 10 days.

Efficacy

Ninety patients with the follow-up period of at least 12 months or longer were included in the clinical outcome analysis. At 6 months post-transplantation all the patients except one responded to treatment: 37 patients (41%) achieved an objective improvement of neurological symptoms and 52 patients (58%) had disease stabilization. In one patient with PPMS disease, progression was registered: EDSS increased from 6.0 at baseline to 6.5 at 6 months post-transplantation. At 12 months after AHSCT, 53% of patients were stable and 43% demonstrated improvement in neurological function. Two more patients progressed: EDSS increase was registered after disease stabilization at 9 and 12 months post-transplantation, respectively. Both patients had SPMS and underwent conventional AHSCT. At long-term follow-up (mean 46 months), the clinical response in 28 patients was classified as an improvement; 31 patients remained stable. At long-term follow-up, progression was found in 11 patients. Three patients progressed after 18 months of stabilization or improvement (two patients with SPMS and one patient with RRMS; all patients underwent conventional AHSCT); three more patients progressed after 24 months of stabilization or improvement (one patient with PPMS, one patient with RRMS, and one patient with SPMS; two patients underwent conventional AHSCT and one patient underwent early AHSCT), one patient progressed after 30 months of stabilization (PPMS; conventional AHSCT), three patients progressed after 36 months of stabilization or improvement (one patient with PPMS and two patients with SPMS; conventional AHSCT in all cases), and one patient progressed after 42 months of stabilization (RRMS; early AHSCT). Overall treatment response at long-term follow-up was 80%.

Figure 1 shows the box and whisker plots depicting the median, 25th and 75th percentile and range of EDSS scores during the follow-up. As seen from Figure 1, a significant decrease of EDSS after AHSCT took place.

The overall clinical response at long-term follow-up was 80%. The vast majority of patients with RRMS were relapse-free (39 of 40). No active, new, or enlarging lesions were registered in patients without disease progression. Remarkably, all patients who did not have disease progression were off therapy throughout the post-transplantation period.

The analysis of probability of progression-free survival, as measured by EDSS change, was performed. Estimated progression-free survival is 82% (confidence interval [CI], 71.2–89.1%) at 5 years (Fig. 2).

Separate analysis of clinical outcomes in the group after early AHSCT and after conventional/salvage AHSCT was performed. In the group after early AHSCT disease progression was registered in only 2 (5%) of 39 patients during the whole period of the follow-up, at 24 and 43 months post-transplantation, respectively. In the group after conventional/salvage AHSCT, 12 (24%) patients progressed at different time points after transplantation. The estimated 5-year progression-free rates were 92% (95% CI, 73–98%) in early AHSCT group and 73% (95% CI, 58–84%) in conventional/salvage AHSCT group. Statistically significant difference between the survival probabilities of two groups was determined (log-rank test, $p = 0.01$, 95% CI; Fig. 3).

QoL monitoring during the entire study period was performed in 61 patients. The results showed remarkable improvement of QoL parameters (Fig. 4). QoL profiles demonstrate dramatic positive changes in patient's QoL after treatment. We found a significant increase of five of eight SF-36 scales (except physical functioning, bodily pain and role-emotional functioning) already at 6 months after ASCT as compared with baseline ($p < 0.05$). Further QoL improvement was registered at 9 and 12 months post-transplantation. QoL parameters at baseline as compared with those at 12 months after AHSCT are presented in Table 2: at 12 months post-transplantation, a statistically

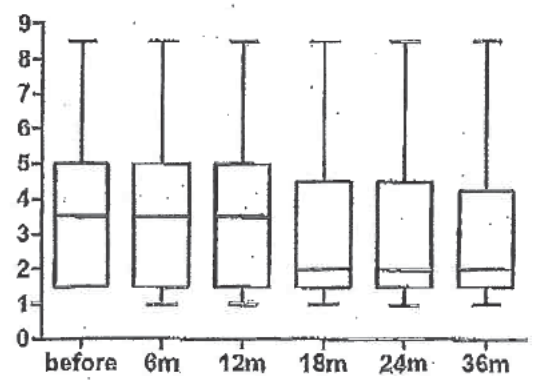

Figure 1. EDSS changes in MS patients before and after AHSCT.

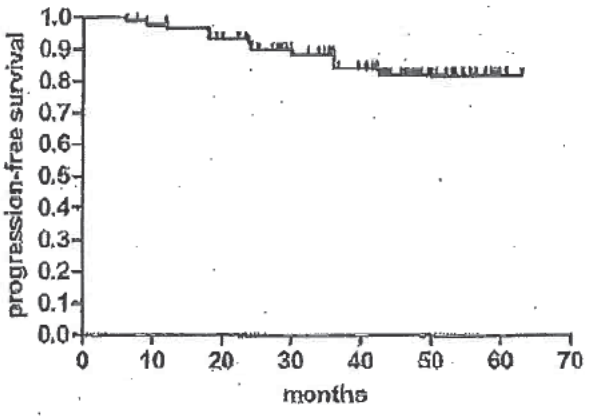

Figure 2. Progression-free survival time after AHSCT.

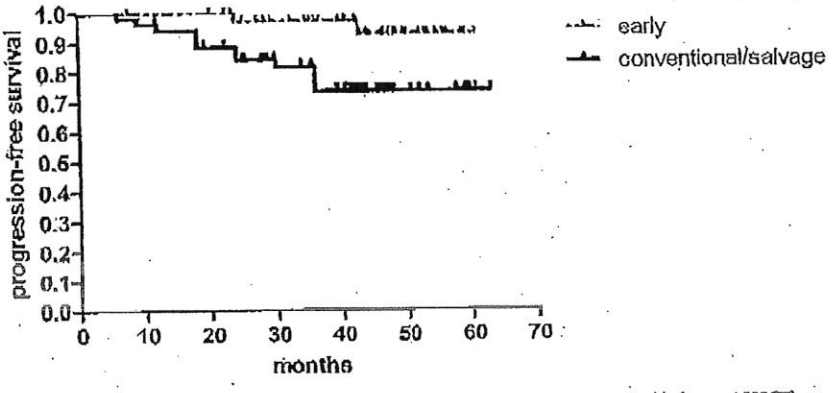

Figure 3. Progression-free survival time after early AHSCT vs conventional/salvage AHSCT.

significant increase of all SF-36 scales, except bodily pain and role-emotional functioning, was registered as compared with baseline ($p < 0.05$). Improved QoL parameters were preserved over the entire study period in all the patients who did not have disease progression.

Discussion

The results of a number of studies demonstrated promising results of MS treatment using HDIT+AHSCT [7,9,13, 14,30,31]. At the same time HDIT+AHSCT is known to be associated with a number of side effects and of major concern is the transplant-related mortality. By now, the most promising results of HDIT+ASCT have been obtained in MS patients with BEAM as a conditioning regimen [16,26]. BEAM is an intermediate-intensity conditioning regimen, pioneered by Fassas et al. [36]. Taking into account serious concerns of neurological community that HDIT+AHSCT is associated with the risk of mortality and adverse effects, as well as published EBMT data about the cases of mortality in MS patients treated with BEAM conditioning regimens, a new reduced-intensity conditioning regimen based on BEAM was proposed, and HDIT+AHSCT with reduced-intensity conditioning was used. We report the results of HDIT+AHSCT with reduced-intensity conditioning for 95 patients with different types and stages of MS.

The results of safety of AHSCT obtained in our study are encouraging. Among 95 patients, there were no transplantation-related deaths. In addition, there were no deaths in our study within the overall follow-up period. As for the adverse effects, the majority of them were limited to the post-transplantation period and were short-lived. There were no severe neurological complications related to the transplantation. Moreover, all adverse effects could be controlled by the transplantation team and were reversible.

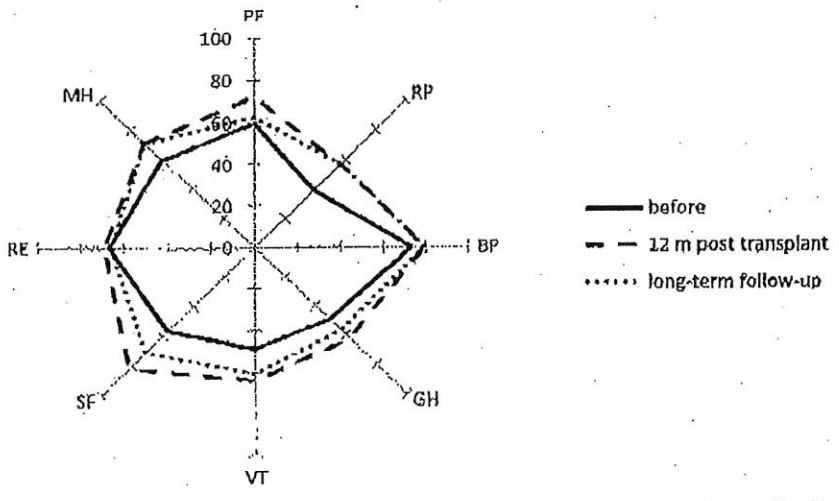

Figure 4. QoL profiles before and at different time points after AHSCT. BP, bodily pain; GH, general health; MH, mental health; PF, physical functioning; RE, role-emotional functioning; RP, role-physical functioning; SF, social functioning; VT, vitality.

Table 2. QoL parameters before and at 12 months after ASCT in MS patients (SF-36 questionnaire)

Scale	Baseline, mean (SD)	12 Months after transplantation, mean (SD)	p Value
Physical functioning	59.7 (30.4)	72.2 (32.4)	0.003*
Role-physical functioning	38.9 (39.9)	56.7 (44.5)	0.03†
Bodily pain	73.2 (24.0)	79.5 (26.6)	0.2
General health	49.4 (22.8)	62.5 (23.3)	0.001*
Vitality	48.8 (21.9)	64.3 (25.3)	0.001*
Social functioning	56.9 (29.4)	82.1 (24.5)	0.0001*
Role-emotional functioning	66.7 (41.4)	68.9 (41.0)	0.4
Mental health	60.0 (23.9)	71.5 (21.8)	0.004*

SD = standard deviation.
*Significant at 99% level CI, $p < 0.01$.
†Significant at 95% level CI, $p < 0.05$.

The efficacy of AHSCT was shown using both clinical outcomes and patient-reported outcomes. The analysis of clinical outcomes demonstrated remarkable results. All of the patients except one responded to the treatment. At long-term follow-up, overall clinical response was 80%. Similar data were found for MS patients treated with BEAM conditioning regimen [16]. Magnetic resonance imaging lesions are a major marker of inflammatory activity. In our group of patients, no active, new, or enlarging lesions were registered in patients without disease progression. Notably, all patients who did not have disease progression were off immunosuppressive or immunomodulatory therapy throughout the post-transplantation period.

In our study, progression-free survival after AHSCT was 82% at 5 years, which is consistent with the results of studies with intermediate and high-intensity conditioning regimens [6,10,16].

The analysis of QoL also demonstrated benefits of AHSCT in this patient population. QoL is an important outcome of MS treatment and its assessment provides the patient's perspective on the overall effect of treatment and allows evaluating patient benefits. Our results definitely show that AHSCT resulted in significant improvement of patient's QoL.

One of the advantages of our study is the performance of transplantation in patients with different stages of MS, including early stages, while most patients in the previous studies had late stages of MS. Our data support the idea that AHSCT is more effective in patients with early stages of active disease. In these patients, autoreactive T cells play a pivotal role in MS pathogenesis. High-dose immunosuppression eradicates autoimmune T cells. It is followed by AHSCT to restore the immune system, which is expected to become tolerant to autoantigens. Such a "resetting" of the immune system is only effective in the early stages of MS, particularly in relapsing-remitting MS. Later in the clinical course of the disease, processes of axonal degeneration prevail, and the damage to CNS tissue is too severe to expect a neurological recovery after HDIT+AHSCT. In our study, the estimated progression-free survival at 5 years was 92% in the group after early AHSCT vs 73% in the group after conventional/salvage AHSCT.

Thus, the risk-to-benefit ratio of HDIT+AHSCT with reduced-intensity conditioning in our population of MS patients is very favorable. The consistency of our clinical and QoL results, together with the persistence of improvement, is in favor of the efficacy of this treatment modality in MS patients. Overall, the results of our study support the feasibility of HDIT+AHSCT in MS patients. Multicenter cooperative studies are needed for better assessment of treatment results and optimization of the treatment protocol of AHSCT with reduced-intensity conditioning regimens in MS.

Acknowledgment

We would like to acknowledge Ruslana V. Kruglina (Moscow) for her contribution to the study.

Conflict of interest disclosure

No financial interest/relationships with financial interest relating to the topic of this article have been declared.

References

1. Weinshenker BG. The natural history of multiple sclerosis. Neurol Clin. 1995;3:119–146.
2. Weinshenker BG, Bass B, Rice GP, et al. The natural history of multiple sclerosis: a geographically based study. I. Clinical course and disability. Brain. 1989;112:133–146.
3. Compston A, Ebers G, Lassmann H, McDonald I, Matthews B, Wekerle H. McAlpine's Multiple Sclerosis. 3rd ed. Edinburgh: Churchill Livingstone; 1998.
4. Hafler DA. Multiple sclerosis. J. Clin Invest. 2004;113:788–794.
5. Kappos L. Therapy. In: Kesselring J, McDonald WI, eds. Multiple Sclerosis. Boston: Cambridge University Press; 1997. p. 148–167.
6. Burt RK, Cohen B, Rose J, et al. Hematopoietic stem cell transplantation for multiple sclerosis. Arch Neurol. 2005;62:860–864.
7. Fassas A, Anagnostopoulos A, Kazis A, et al. Autologous stem cell transplantation in progressive multiple sclerosis—an interim analysis of efficacy. J Clin Immunol. 2000;20:24–30.
8. Brenner MK. Haematopoietic stem cell transplantation for autoimmune disease: limits and future potential. Best Pract Res Clin Haematol. 2004;17:359–374.
9. Burt RK, Cohen BA, Russell E, et al. Hematopoietic stem cell transplantation for progressive multiple sclerosis; failure of a total body irradiation-based conditioning regimen to prevent disease progression in patients with high disability scores. Blood. 2003;102:2373–2378.
10. Burt RK, Cohen B, Lobeck L, Traynor AE. Autologous hematopoietic stem cell transplantation in multiple sclerosis: importance of disease stage on outcome [abstract]. Neurology. 2003;40(suppl). Abstract 150.
11. Fassas A, Nash R. Multiple sclerosis. Best Pract Res Clin Hematol. 2004;17:247–262.
12. Fassas A, Passweg JR, Anagnostopoulos A, et al. Hematopoietic stem cell transplantation for multiple sclerosis. A retrospective multicenter study. J Neurol. 2002;249:1088–1097.
13. Kozak T, Havrdova E, Pit'ha J, et al. High-dose immunosuppressive therapy with PBPC support in the treatment of poor risk multiple sclerosis. Bone Marrow Transplant. 2000;25:S28–S31.

14. Nash RA, Bowen JD, McSweeney PA, et al. High-dose immunosuppressive therapy and autologous peripheral blood stem cell transplantation for severe multiple sclerosis. Blood. 2003;102:2364–2372.
15. Freedman M, Atkins H, Arnold D, Bar-Or A; on behalf of the Canadian BMT Study Group. Immunoablation and autologous stem cell transplantation for aggressive multiple sclerosis: interim 5-year report. Mult Scler. 2007;13(suppl 2):S22. (abstract).
16. Saccardi R, Kozak T, Tyndall C, et al. Autologous stem cell transplantation for progressive multiple sclerosis: update of the European Group for Blood and Marrow Transplantation Autoimmune Diseases Working Party database. Mult Scler. 2006;12:814–823.
17. Ni XS, Ouyang J, Zhu WH, Wang C, Chen B. Autologous hematopoietic stem cell transplantation for progressive multiple sclerosis: report of efficacy and safety at three yr of follow up in 21 patients. Clin Transplant. 2006;20:485–489.
18. Krasulova E, Trneny M, Kozak T, et al. High-dose immunoablation with autologous haematopoietic stem cell transplantation in aggressive multiple sclerosis: a single centre 10-year experience. Mult Scler. 2010;16:685–693.
19. Harnersohlak N, Rodrigues M, Moraes DA, et al. Brazilian experience with two conditioning regimens in patients with multiple sclerosis: BEAM/horse ATG and CY/rabbit ATG. Bone Marrow Transplant. 2010;45:239–248.
20. Burt R, Loh Y, Cohen B, et al. Autologous non-myeloablative haemopoietic stem cell transplantation in relapsing–remitting multiple sclerosis: a phase I/II study. Lancet Neurol. 2009;8:244–253.
21. Comi G, Kappos L, Clanet M, et al. Guidelines for autologous blood and marrow stem cell transplantation in multiple sclerosis: a consensus report written on behalf of the European Group for Blood and Marrow Transplantation and the European Charcot Foundation. J Neurol. 2000;247:376–382.
22. Mancardi G, Saccardi R. Autologous haematopoietic stem-cell transplantation in multiple sclerosis. Lancet Neurol. 2008;7:626–636.
23. Tyndall A, Fassas A, Passweg J, et al. Autologous haematopoietic stem cell transplants for autoimmune disease—feasibility and transplant-related mortality. Autoimmune Disease and Lymphoma Working Parties of the European Group for Blood and Marrow Transplantation, the European League Against Rheumatism and the International Stem Cell Project for Autoimmune Disease. Bone Marrow Transplant. 1999;24:729–734.
24. Gratwohl A, Passweg J, Bocelli-Tyndall C, et al. Autologous hematopoietic stem cell transplantation for autoimmune diseases. Bone Marrow Transplant. 2005;35:869–879.
25. Burt RK, Marmont A, Oyama Y, et al. Randomized controlled trials of autologous hematopoietic stem cell transplantation for autoimmune diseases: the evolution from myeloablative transplant regimens. Arthritis Rheum. 2006;54:3750–3760.
26. Reston JT, Uhl S, Treadwell JR, Nash RA, Schoelles K. Autologous hematopoietic cell transplantation for multiple sclerosis: a systematic review. Mult Scler. 2011;17:204–213.
27. Saccardi R, Mancardi GL, Solari A, et al. Autologous HSCT for severe progressive multiple sclerosis in a multicenter trial: impact on disease activity and quality of life. Blood. 2005;105:2601–2607.
28. Novik A, Ionova T, Bisaga G, et al. Clinical and quality of life responses to high-dose chemotherapy plus autologous stem cell transplantation in patients with multiple sclerosis: two case reports. Cytotherapy. 2005;7:363–367.
29. Shevchenko Y, Novik A, Kuznetsov A, et al. High-dose immunosuppressive therapy with autologous hematopoietic stem cell transplantation as a treatment option in multiple sclerosis. Exp Hematol. 2008;36:922–929.
30. Chen B, Zhou M, Ouyang J, et al. Long-term efficacy of autologous haematopoietic stem cell transplantation in multiple sclerosis at a single institution in China. Neurol Sci. 2012;33(suppl 4):881–886.
31. Snowden JA, Saccardi R, Allez M, et al. Haematopoietic SCT in severe autoimmune disease: updated guidelines of the European Group for Blood and Marrow Transplantation. Bone Marrow Transplant. 2012;47:770–790.
32. Rogojan C, Frederiksen JL. Hematopoietic stem cell transplantation in multiple sclerosis. Acta Neurol Scand. 2009;120:371–382.
33. Murare PA, McFarland HF, Martin R. Immunological aspects of multiple sclerosis with emphasis on the potential use of autologous hemopoietic stem cell transplantation. In: Burt RK, Marmont AM, eds. Stem Cell Therapy for Autoimmune Disease. Georgetown, TX: Landes Bioscience; 2004. p. 277–283.
34. McDonald WI, Compston A, Edan G, et al. Recommended diagnostic criteria for multiple sclerosis: guidelines from the International Panel on the diagnosis of multiple sclerosis. Ann Neurol. 2001;50(suppl 1):121–127.
35. Hays RD, Sherbourne CD, Mazel RM. User's Manual for Medical Outcomes Study (MOS) Core measures of health-related quality of life. RAND Corporation, MR-162-RC. Available at: http://www.rand.org. Accessed 1995.
36. Fassas A, Anagnostopoulos A, Kasis A, et al. Peripheral blood stem cell transplantation in the treatment of progressive multiple sclerosis: first results of a pilot study. Bone Marrow Transplant. 1997;20:631–638.

Enter Penalties and Allowances | Return to Operating Budget

Show Budgeted Lines Only | Show All Budget Lines

Salary Budgeting Template
2018-2019
Budget
Cost Centre: 61751 - Neurology Unit

ACT Government Health

Printed 28 June 2019

View instructions

Salary Level	Salary Level Description	Casual or Perm't	Full Time Equivalent (FTE) per Salary Level												Comments	Superannuation			
			Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Year		CSS	PSS	PSSAP	Fund of Choice
	Enter description below for each level	*Select C or P*	*Enter Number of FTE's per Salary Level per month*												*Enter Comments for FTE input below*	*Unentered FTE's will default to PSS*			
ASO3.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP3.2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
TTO.6		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R4		P	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00		-	-	-	2.00
R4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP4.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40		-	-	-	0.40
ASO4.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
ASO3.1		P	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60		-	-	-	0.60
HP2.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
RN2.3		P	0.53	0.53	0.53	0.53	0.53	0.53	0.53	0.53	0.53	0.53	0.53	0.53	0.53		-	0.00	-	0.53
RN3G1.5		P	1.06	1.06	1.06	1.06	1.06	1.06	1.06	1.06	1.06	1.06	1.06	1.06	1.06		-	0.00	-	1.06
Total FTE's			15.59	15.59	15.59	15.59	15.59	15.59	15.59	15.59	15.59	15.59	15.59	15.59	15.59		-	4.00	-	11.59

	Year
Revenues	(143,172)
Expense	3,159,689
Labour	3,051,532
Operating Expenses	108,157

Enter Penalties and Allowances | Return to Operating Budget
Show Budgeted Lines Only | Show All Budget Lines

Salary Budgeting Template
2017-2018
Budget
Cost Centre: 61751 - Neurology Unit

ACT Government Health

Printed 28 June 2019

View instructions

Salary Level	alary Level Descriptic	Casual or Perm't	Full Time Equivalent (FTE) per Salary Level												Comments	Superannuation			
			Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Year		CSS	PSS	PSSAP	Fund of Choice
	ter description below for each le	Select C or P	Enter Number of FTE's per Salary Level per month												Enter Comments for FTE input below	Unentered FTE's will default to PSS			
ASO3.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP3.2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
TTO.6		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R4		P	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00		-	-	-	2.00
R4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP4.3		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40		-	-	-	0.40
ASO4.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
ASO3.1		P	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60		-	-	-	0.60
HP2.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Total FTE's			14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00		-	4.00	-	10.00

	Year
Revenues	(139,680)
Expense	2,699,904
Labour	2,545,434
Operating Expenses	154,470

Enter Penalties and Allowances | Return to Operating Budget

Show Budgeted Lines Only | Show All Budget Lines

Salary Budgeting Template
2016-2017
Budget
Cost Centre: 61751 - Neurology Unit

ACT Government Health

Printed 26 June 2019

View Instructions

Salary Level	lary Level Descripti	Casual or Perm't	Full Time Equivalent (FTE) per Salary Level												Comments	Superannuation			
			Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Year		CSS	PSS	PSSAP	Fund of Choice
	r description below for each	Select C or P	Enter Number of FTE's per Salary Level per month												Enter Comments for FTE input below	Unentered FTE's will default to PSS			
ASO3.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP5.2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
TTO.6		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP4.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40		-	-	-	0.40
ASO4.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
ASO3.1		P	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60		-	-	-	0.60
HP2.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Total FTE's			12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00		-	4.00	-	8.00

	Year
Revenues	(135,941)
Expense	2,293,510
Labour	2,155,324
Operating Expenses	138,187

Enter Penalties and Allowances | Return to Operating Budget

Show Budgeted Lines Only | Show All Budget Lines

Salary Budgeting Template
2015-2016
Budget
Cost Centre: 61751 - Neurology Unit

ACT Government
Health

Printed 26 June 2019

View instructions

Salary Level	lary Level Descripti	Casual or Perm't	Full Time Equivalent (FTE) per Salary Level												Comments	Superannuation			
			Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Year		CSS	PSS	PSSAP	Fund of Choice
	r description below for each	Select C or P	Enter Number of FTE's per Salary Level per month												Enter Comments for FTE input below	Unentered FTE's will default to PSS			
ASO3.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP3.2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
TTO.6		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP4.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40		-	-	-	0.40
ASO4.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
ASO3.1		P	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60		-	-	-	0.60
HP2.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Total FTE's			12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00	12.00		-	4.00	-	8.00

	Year
Revenues	(133,601)
Expense	2,236,530
Labour	2,104,470
Operating Expenses	132,060

Enter Penalties and Allowances | Return to Operating Budget

Show Budgeted Lines Only | Show All Budget Lines

Salary Budgeting Template
2014-2015
Budget
Cost Centre: 61751 - Neurology Unit

ACT Government Health

Printed 28 June 2019

View Instructions

Salary Level	lary Level Descripti	Casual or Perm't	Full Time Equivalent (FTE) per Salary Level												Comments	Superannuation			
			Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Year		CSS	PSS	PSSAP	Fund of Choice
	r description below for each	Select C or P	Enter Number of FTE's per Salary Level per month												Enter Comments for FTE input below	Unentered FTE's will default to PSS			
AS03.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP3.2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
TT0.6		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R2		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	-	-	0.83		-	0.00	-	0.83
R4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
HP4.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	1.00	-	-
RMO4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	-	-	0.83		-	0.00	-	0.83
Snr Specialist		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Snr Specialist		P	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40	0.40		-	-	-	0.40
AS04.1		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
AS03.1		P	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60	0.60		-	-	-	0.60
HP2.4		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
R3		P	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00		-	-	-	1.00
Total FTE's			14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00	14.00	12.00	12.00	13.67		-	4.01	-	9.66

	Year
Revenues	(235,473)
Expense	2,380,959
Labour	2,247,226
Operating Expenses	133,733

Noffke, Kellie (Health)

From: Lahoria, Rajat (Health)
Sent: Friday, 16 November 2018 22:32
To: Noffke, Kellie (Health)
Cc: Forbes, Elizabeth (Health); Lueck, Christian (Health); Talaulikar, Girish (Health)
Subject: RE: MS Nurse ACTH [SEC=UNCLASSIFIED]

Importance: High

Dear Kellie,

[redacted]

Kind regards,
Rajat

From: Lahoria, Rajat (Health)
Sent: Monday 12 November 2018 18:50
To: Noffke, Kellie (Health)
Cc: Forbes, Elizabeth (Health); Lueck, Christian (Health); Talaulikar, Girish (Health)
Subject: RE: MS Nurse ACTH [SEC=UNCLASSIFIED]

Dear Kellie,

Many thanks for your response. It is much appreciated.

The issue about the RN level was explicitly raised by Christian with Marina prior to the job being advertised but we were reassured that it would not be a problem. It is not surprising that not suitable candidate applied for the position as it was under- classified. I had no say in this neither I think did Christian.

[redacted]

I am interested in how we can move forwards and address this as a priority.

Please let me know how we can proceed now that I have clarified the situation. I look forward to your response.

Kind regards,
Rajat

From: Noffke, Kellie (Health)
Sent: Monday 12 November 2018 09:59
To: Lahoria, Rajat (Health)
Cc: Forbes, Elizabeth (Health); Lueck, Christian (Health); Talaulikar, Girish (Health)
Subject: RE: MS Nurse ACTH [SEC=UNCLASSIFIED]

Dear Rajat

Previously there was a RN level 2 part time MS nurse employed and funded by the MS Society, however this position ended. Within the Division of Medicine we were able to fund a RN Level 2 0.5 FTE position, which is what we currently have.

[redacted]

Kind Regards

Kellie

From: Lahoria, Rajat (Health)
Sent: Wednesday, 7 November 2018 10:32 PM
To: Noffke, Kellie (Health) <Kellie.Noffke@act.gov.au>
Cc: Forbes, Elizabeth (Health) <Elizabeth.Forbes@act.gov.au>; Lueck, Christian (Health) <Christian.Lueck@act.gov.au>; Division Of Medicine Management <DivisionOfMedicineManagement@act.gov.au>; Talaulikar, Girish (Health) <Girish.Talaulikar@act.gov.au>
Subject: FW: MS Nurse ACTH
Importance: High

Dear Kellie,

I have received a letter from the DG dated 13 October 2018 which I am unable to share due to unrelated confidential information included in this letter. One of the important issues discussed is the appointment and recruitment of the MS nurse at TCH. DG's viewpoint is that the appointment of the MS nurse was made with my agreement although the reality is that I had expressed strong reservations regarding this appointment from the onset and insisted that it should only happen on a trial basis which everyone agreed and is well documented. Despite my repeated requests for more than a year there has been no evaluation of this trial period or how the MS service continues to be affected by this arrangement. I would be most grateful if you can respond to my email from 8 September 2018 and endeavour to provide answers to the questions I have raised.

I look forward to your response at your earliest connivence. Please feel to ask me if there are any questions. I would be most grateful if you can acknowledge the receipt of my email request.

Kind regards,
Rajat

From: Lahoria, Rajat (Health)
Sent: Saturday 8 September 2018 18:07
To: Noffke, Kellie (Health)
Cc: Forbes, Elizabeth (Health); Lueck, Christian (Health); Division Of Medicine Management
Subject: MS Nurse ACTH

Dear Kellie,

Hope this email finds you well.

I would be most grateful if you could provide me with an official update regarding the ACTH MS nurse position at your earliest convenience. As you must be well aware that the current MS nurse appointment was on a trial basis [redacted] Needless to say, the position was under classified, so it would not have been possible to attract any suitable candidates anyway. This is the feedback I received from the many specialist nurses whom I spoke to subsequently, and also from MS Australia.

[redacted] The position is also half time which is problematic and there is also no backfill to cover leave. This continues to place additional burden on me and also has implications for quality of care and patient safety. I believe you were officially updated on this matter by Professor Lueck sometime around June 2017.

I hereby attach the document containing the relevant email trail. Further email evidence is available if required. I hereby request answers to the following questions:

1) Why has your office never considered it was necessary to check even once if the trial appointment worked? It has now been 18 months into the trail!

2) Compared to the duties listed in the proposed duty statement (pages 4 of the attached document) to the list of MS nurse duties I provided to Professor Lueck in June 2017 at his request (page 9 of the attached document), which specific duties require RN level 3 RN classification as opposed to RN level 2 classification?

3) Was the proposed duties statement reviewed by HR in 2016 prior to the job being advertised and were the listed duties considered appropriate for RN level 2 classification? If so, could I please obtain a copy of the HR report?

[redacted]

I hope this is not too much to ask for, but I am sure you will appreciate I am desperate for some answers so that I can escalate this matter to a higher level. Clearly this situation is not acceptable and the response/information I has received so far is far from satisfactory.

I look forward to hearing from you soon.

Kind regards,
Rajat

Noffke, Kellie (Health)

From: Lueck, Christian (Health)
Sent: Wednesday, 14 November 2018 10:20
To: Noffke, Kellie (Health)
Cc: Talaulikar, Girish (Health)
Subject: RE: Re: MS Nurse Role [SEC=UNCLASSIFIED]

Thanks, Kellie.
I'll wait to hear from you.
Please let me know if there is anything I can do.
Kind regards, Christian

From: Noffke, Kellie (Health)
Sent: Wednesday, 14 November 2018 9:19 AM
To: Lueck, Christian (Health) <Christian.Lueck@act.gov.au>
Cc: Talaulikar, Girish (Health) <Girish.Talaulikar@act.gov.au>
Subject: RE: Re: MS Nurse Role [SEC=UNCLASSIFIED]

Hi Christian

[redacted]

Thanks

Kellie

From: Lueck, Christian (Health)
Sent: Wednesday, 14 November 2018 8:23 AM
To: Noffke, Kellie (Health) <Kellie.Noffke@act.gov.au>
Cc: Talaulikar, Girish (Health) <Girish.Talaulikar@act.gov.au>
Subject: FW: Re: MS Nurse Role [SEC=UNCLASSIFIED]

Dear Kellie,

[redacted]

Many thanks for your help.
Kind regards, Christian

From: Lahoria, Rajat (Health)
Sent: Tuesday, 13 November 2018 10:50 PM
To: Janea, Marie (Health) <Marie.Janea@act.gov.au>; Noffke, Kellie (Health) <Kellie.Noffke@act.gov.au>
Cc: Forbes, Elizabeth (Health) <Elizabeth.Forbes@act.gov.au>; Maburuse, Zivai (Health) <Zivai.Maburuse@act.gov.au>; Lueck, Christian (Health) <Christian.Lueck@act.gov.au>; Talaulikar, Girish (Health) <Girish.Talaulikar@act.gov.au>
Subject: RE: Re: MS Nurse Role [SEC=UNCLASSIFIED]

Dear Marie,

Thanks for including me in your email. I hope you don't mind me clarifying what I believe might have led to this email. Please correct me if you disagree with anything or if I have misunderstood anything. I have included Christian and Girish in the email to keep them in the loop.

I look forward to input from others to see what can be done to improve matters.

Kind regards,
Rajat

From: Janea, Marie (Health)
Sent: Tuesday 13 November 2018 12:15
To: Noffke, Kellie (Health)
Cc: Lahoria, Rajat (Health); Forbes, Elizabeth (Health); Maburuse, Zivai (Health)
Subject: Re: MS Nurse Role [SEC=UNCLASSIFIED]

Dear Kellie,

Good day!

Sincerely yours,
Marie Janea

Noffke, Kellie (Health)

From: Lueck, Christian (Health)
Sent: Tuesday, 19 December 2017 16:32
To: Forbes, Elizabeth (Health)
Cc: Noffke, Kellie (Health)
Subject: RE: MS nurse question [SEC=UNCLASSIFIED]

Thanks, Beth.

That all sounds good.

If someone can obtain a quote for the vital sign machine, I would be happy to look at purchasing it from the neurology budget.

Many thanks.

Kind regards, Christian

From: Forbes, Elizabeth (Health)
Sent: Tuesday, 19 December 2017 4:13 PM
To: Lueck, Christian (Health) <Christian.Lueck@act.gov.au>
Cc: Noffke, Kellie (Health) <Kellie.Noffke@act.gov.au>
Subject: RE: MS nurse question [SEC=UNCLASSIFIED]

Hi Christian,

Marie and I had our catch up this afternoon.
She reports that she has 5 patients on Alemtuzumab, all under Dr Lahoria.
I relayed the advice provided form you, that being Marie to look after all the Alemtuzumab patients in the ACT, provided they are having their treatments here at TCH; and that Marie shouldn't get involved with any other medication at this point.
Marie was happy with this.
Marie and I will remain in communication about workload, and I can pass on any concerns to you and Kellie.

One other issue that was raised was the lack of access to a vital signs machine in the outpatient clinics. Is it possible to purchase a portable vital signs machine for Marie to use in the Tuesday and Friday clinic? A portable one would be best, as then it can be taken up to her office on the days she is not the MS nurse so that it does not go missing.

Kind regards,
Beth

From: Lueck, Christian (Health)
Sent: Wednesday, 13 December 2017 4:15 PM
To: Forbes, Elizabeth (Health) <Elizabeth.Forbes@act.gov.au>; Noffke, Kellie (Health) <Kellie.Noffke@act.gov.au>
Subject: RE: MS nurse question [SEC=UNCLASSIFIED]

Thanks, Beth.

I am very sorry to have been so slow getting back to you.

I had wanted to speak to Rajat before taking this forward.

I also wanted to find out how much actual work was involved from Marie.
Unfortunately, I have managed to do neither!

If the amount of additional work involved is relatively small, then I think it would be reasonable to ask Marie to look after all the Alemtuzumab patients in the ACT, provided they are having their treatments here at TCH, of course. If, however, this is going to be a significant additional burden to an already overloaded 0.5FTE MS nurse, then I think it would be reasonable to say that, as she is currently part-time in the post, she doesn't have the capacity to deal with any patients other than Rajat's. I certainly don't think Marie should get involved with any other medication at this point, incidentally.

Could you speak to Marie when you see her next week about what the actual impact on her workload would be if she were to take on all patients on Alemtuzumab? This should allow us to make an informed decision. I will continue to try to speak to Rajat and will let you know if I have any further information/input.

Apologies again for taking so long to get back to you.

Kind regards, Christian

From: Forbes, Elizabeth (Health)
Sent: Wednesday, 13 December 2017 3:02 PM
To: Lueck, Christian (Health) <Christian.Lueck@act.gov.au>; Noffke, Kellie (Health) <Kellie.Noffke@act.gov.au>
Subject: FW: MS nurse question [SEC=UNCLASSIFIED]

Hi Christian and Kelly,

I am meeting with Marie next Tuesday afternoon. I would really like to offer her some guidance on how to manage the requests from other doctors to look after their MS patients. Can you please provide me with some advice on what to tell her.

Kind regards,
Beth

CANBERRA HOSPITAL
AND HEALTH SERVICES

Elizabeth Forbes | Clinical Nurse Consultant/ Nurse Manager
Chronic Care Program | Canberra Hospital & Health Services
P +612 6174 5289 [redacted]
A Building 1 Level 8A | PO Box 11 WODEN ACT 2606
E elizabeth.forbes@act.gov.au **W** www.health.act.gov.au

Please note I work part time Monday- Wednesday

From: Forbes, Elizabeth (Health)
Sent: Tuesday, 5 December 2017 1:02 PM
To: Noffke, Kellie (Health) <Kellie.Noffke@act.gov.au>; Lueck, Christian (Health) <Christian.Lueck@act.gov.au>
Subject: RE: MS nurse question [SEC=UNCLASSIFIED]

Hi Christian and Kelly,

Thanks for getting back to me.

Marie has told me that there are currently 5 patients on Lemtrada that are Dr Lahoria's. She is unaware of the numbers for other consultants including Dr Malhotra.

It is not only patients on Lemtrada that she is being asked to have input into, it is other infusions as well. Marie was contacted by the HITH nurse to come and review and educate a patient who was commencing on Gilenya. This was a Dr Colin Andrews patient from his private rooms. Luckily, this patient was in HITH on the day Marie was working as the MS nurse and so she could provide the needed support to this patient.

This shows that the MS nurse role is a valuable position and many patients could benefit from her input. At this stage,

[redacted]

Kind regards,
Beth

From: Noffke, Kellie (Health)
Sent: Friday, 1 December 2017 3:19 PM
To: Lueck, Christian (Health) <Christian.Lueck@act.gov.au>
Cc: Forbes, Elizabeth (Health) <Elizabeth.Forbes@act.gov.au>
Subject: Re: MS nurse question [SEC=UNCLASSIFIED]

Thank you Christian and Beth and I share your concerns

I will wait for further information.

Kind Regards

Kellie

Sent from my iPhone

On 1 Dec 2017, at 14:49, Lueck, Christian (Health) <Christian.Lueck@act.gov.au> wrote:

> Thanks, Beth.
>
> (Sorry, I was away yesterday)
>
> [redacted]
>
> Kind regards, Christian

From: Forbes, Elizabeth (Health)
Sent: Wednesday, 29 November 2017 5:01 PM
To: Noffke, Kellie (Health) <Kellie.Noffke@act.gov.au>; Lueck, Christian (Health) <Christian.Lueck@act.gov.au>
Subject: MS nurse question [SEC=UNCLASSIFIED]

Dear Kellie and Christian,

[redacted]

Kind regards,
Beth

<image001.jpg> <image002.jpg>

Elizabeth Forbes | Clinical Nurse Consultant/ Nurse Manager
Chronic Care Program | Canberra Hospital & Health Services
P +612 6174 5289 [redacted]
A Building 1 Level 8A | PO Box 11 WODEN ACT 2606
E elizabeth.forbes@act.gov.au **W** www.health.act.gov.au

Please note I work part time Monday- Wednesday

Noffke, Kellie (Health)

From: Lahoria, Rajat (Health)
Sent: Thursday, 10 August 2017 19:19
To: Noffke, Kellie (Health); Maburuse, Zivai (Health)
Cc: Lueck, Christian (Health); Abhayaratna, Walter (Health); Chatham, Elizabeth (Health); McMaster, Kathryn (Health); Buchanan-Grey, Marina (Health)
Subject: RE: MS nurse roster [SEC=UNCLASSIFIED]

Dear Kellie,

I am most grateful for your swift response on this matter.

Much appreciated.
Rajat

From: Noffke, Kellie (Health)
Sent: Thursday 10 August 2017 17:06
To: Lahoria, Rajat (Health); Maburuse, Zivai (Health)
Cc: Lueck, Christian (Health); Abhayaratna, Walter (Health); Chatham, Elizabeth (Health); McMaster, Kathryn (Health); Buchanan-Grey, Marina (Health)
Subject: RE: MS nurse roster [SEC=UNCLASSIFIED]

Hi Rajat

[redacted]

Kind Regards

Kellie

From: Lahoria, Rajat (Health)
Sent: Thursday, 10 August 2017 11:49 AM
To: Maburuse, Zivai (Health); Noffke, Kellie (Health)
Cc: Lueck, Christian (Health); Abhayaratna, Walter (Health); Chatham, Elizabeth (Health); McMaster, Kathryn (Health); Buchanan-Grey, Marina (Health)
Subject: MS nurse roster [SEC=UNCLASSIFIED]

Dear Zivai and Kellie,

[redacted]

As I have previously mentioned Thursdays are the only days I have dedicated admin time when Marie and I can go over issues together and it is also the only opportunity for me to train her.

[redacted]

If there is shortage of nurses on the neurology wards then there has to be another solution for this problem.

I look forward to hearing from you.

Kind regards,
Rajat

Noffke, Kellie (Health)

From: Noffke, Kellie (Health)
Sent: Tuesday, 20 June 2017 15:20
To: McMaster, Kathryn (Health)
Subject: RE: MS nurse [SEC=UNCLASSIFIED]

Great Kath. That sounds very positive. Yes happy for you to sign the papers to submit.
Cheers
Kellie

From: McMaster, Kathryn (Health)
Sent: Tuesday, 20 June 2017 2:41 PM
To: Noffke, Kellie (Health)
Subject: MS nurse

Hi Kellie,

[redacted]

Kath McMaster
CNC Ward 7A
Canberra Hospital & Health Services
6244 3022
Red Contact Officer

ACT Government Health | CANBERRA HOSPITAL AND HEALTH SERVICES

Care ▲ Excellence ▲ Collaboration ▲ Integrity

Noffke, Kellie (Health)

From: Mossman, Wendy (Health)
Sent: Wednesday, 31 May 2017 11:40
To: Noffke, Kellie (Health); Lueck, Christian (Health)
Subject: RE: MS Nurse line management [SEC=UNCLASSIFIED]

Hi Kellie & Christian

[redacted]

Regards

Wendy Mossman
Ag Assistant Director of Nursing, Ambulatory Services
Division of Medicine
Canberra Hospital B24/ L2
Phone: 02 61745164

E-mail: wendy.mossman@act.gov.au
Care ▲ Excellence ▲ Collaboration ▲ Integrity

From: Noffke, Kellie (Health)
Sent: Wednesday, 31 May 2017 9:19 AM
To: Lueck, Christian (Health)
Cc: Mossman, Wendy (Health)
Subject: RE: MS Nurse line management [SEC=UNCLASSIFIED]

Hi Christian

For the MS component of Marie's job her direct report is the CNC of Chronic Care. At present the acting CNC is Helen McFarlane but the substantive CNC is Beth Forbes [redacted]

I think Helen would be happy to sit down with Marie and Rajat. Marie is in a RN level 2 position so it is important she is practising within her scope of practice.

Thanks

Kellie

From: Lueck, Christian (Health)
Sent: Tuesday, 30 May 2017 5:38 PM
To: Noffke, Kellie (Health)
Subject: MS Nurse line management

Dear Kellie,

I wonder if I could ask your help, please?

Thank you very much indeed.

Best wishes, Christian

Noffke, Kellie (Health)

From: Lahoria, Rajat (Health)
Sent: Monday, 10 April 2017 13:31
To: Lueck, Christian (Health)
Cc: Noffke, Kellie (Health)
Subject: Re: Educational support for MS Nurse [SEC=UNCLASSIFIED]

Dear Christian and Kellie,
I don't think there is any conflict if interest. My understanding is that the conference is a few months away. Hence I would encourage Marie to go through the process in order to attend it.
Many thanks,
Rajat

Sent from my iPhone

On Apr 10, 2017, at 12:11 PM, Lueck, Christian (Health) <Christian.Lueck@act.gov.au> wrote:

> Thanks, Kellie.
> That's very helpful.
> Rajat, do you think that either the conference or Biogen support would represent a significant conflict of interest in relation to managing MS patients?
> Best wishes, Christian
>
> ---
>
> **From:** Noffke, Kellie (Health)
> **Sent:** Monday, 10 April 2017 11:55 AM
> **To:** Lueck, Christian (Health)
> **Subject:** RE: Educational support for MS Nurse [SEC=UNCLASSIFIED]
>
> Hi Christian
>
> Approval will need to be given by Patricia O'Farrell ED People and Culture after it has been through our ED first. This is usually done through the person requesting attaching a minute with all their signed off conference paperwork. There is usually no issue unless there is a conflict of interest. If you think there is a conflict of issue then we should not pursue. If you would like it to progress it may take some time to go through all the appropriate channels, I'm not sure when the conference is so I don't know if this is an issue.
>
> Kind Regards
>
> Kellie
>
> ---
>
> **From:** Lueck, Christian (Health)
> **Sent:** Sunday, 9 April 2017 12:59 PM
> **To:** Noffke, Kellie (Health)
> **Subject:** FW: Educational support for MS Nurse
>
> Dear Kellie,
>
> See below.

Biogen have offered to sponsor Marie's attendance at the MS nurses' association conference. I wasn't sure what the hospital's position regarding support for nurses like this was.

Could you possibly advise?

Many thanks.

Kind regards, Christian

From: [redacted]
Sent: Thursday, 6 April 2017 7:40 AM
To: Lueck, Christian (Health)
Subject: Educational support for MS Nurse

Good morning Christian,

Hope you are well? I am just following up a discussion regarding support for the Marie, the MS Nurse at TCH to attend the MSNA Conference in Hobart - you needed to check the hospital's position on accepting this type of support.

Do you have any further information to that end?

Happy to provide assistance if we can.

Very best regards,

[redacted]

Senior Area Business Manager NSW, ACT - Tysabri/Zinbryta
Team Leader, QLD
Biogen Australia and NZ | Level 3, 123 Epping Road | North Ryde, NSW 2113| Australia
[redacted]
www.biogen.com

Noffke, Kellie (Health)

From: Noffke, Kellie (Health)
Sent: Monday, 20 February 2017 17:04
To: McFarlane, Helen (Health)
Cc: Flaherty, Hannah (Health)
Subject: RE: MS nurse training in Sydney [SEC=UNCLASSIFIED]

It will be the cost centre we remote Marie out to from 7A. I would imagine there would just be costs of flights. If you submit all the paperwork to me and I can get Liz to sign off.

Thanks

Kellie

From: McFarlane, Helen (Health)
Sent: Monday, 20 February 2017 2:57 PM
To: Noffke, Kellie (Health)
Cc: Flaherty, Hannah (Health)
Subject: MS nurse training in Sydney [SEC=UNCLASSIFIED]

Hello Kellie,
I am hoping to complete an application for travel to Sydney for Marie Janea (MS nurse) to spend 2 separate days at the Brain and Mind Institute in the month of March, in order to attend their MS clinics to further develop her skills.
I was under the impression that Marina had in principle supported the training and the costs to send her.
So we can complete and then submit the paperwork to you, would you be able to advise me which **cost centre** would be assigned the costs?

Is it Neurology ?

Many thanks Kellie.

Regards,
Helen

CANBERRA HOSPITAL
AND HEALTH SERVICES

Helen McFarlane | Acting Clinical Nurse Consultant/ Nurse Manager
Chronic Care Program | Canberra Hospital & Health Services
P +612 6174 5289 [redacted]
A Building 1 Level 8A | PO Box 11 WODEN ACT 2606
E helen.mcfarlane@act.gov.au **W** www.health.act.gov.au

Noffke, Kellie (Health)

From: Lahoria, Rajat (Health)
Sent: Thursday, 9 February 2017 16:49
To: Noffke, Kellie (Health); Maburuse, Zivai (Health)
Subject: RE: MS POSITION [SEC=UNCLASSIFIED]

Thanks, Kellie. Milly should be able to provide you this information. I will send her a separate email.

Thanks,
Rajat

From: Noffke, Kellie (Health)
Sent: Thursday, 9 February 2017 4:48 PM
To: Lahoria, Rajat (Health); Maburuse, Zivai (Health)
Subject: RE: MS POSITION [SEC=UNCLASSIFIED]

Thanks Rajat. Who is the secretary so Zivai can make contact and try and match a roster to your schedule? We will do our very best to try and match this.
Thanks
Kellie

From: Lahoria, Rajat (Health)
Sent: Thursday, 9 February 2017 4:22 PM
To: Noffke, Kellie (Health); Maburuse, Zivai (Health)
Subject: RE: MS POSITION [SEC=UNCLASSIFIED]

Thanks, Kellie. Actually that would work fine too. As long as the Thursdays she works in the capacity of MS nurse coincides with the Thursdays I do not have a clinic. Our neurology secretary should be able to provide my clinic schedule.

Thanks,
Rajat

From: Noffke, Kellie (Health)
Sent: Thursday, 9 February 2017 4:19 PM
To: Maburuse, Zivai (Health); Lahoria, Rajat (Health)
Subject: RE: MS POSITION [SEC=UNCLASSIFIED]

Hi Rajat and Zivai

Unfortunately we will not be able to roster Marie this way. Firstly it will breach EBA requirements and secondly it will not work operationally for 7a. I think at this point the best we can offer is for Marie to work three full days one week and two the next week. This would be Tuesday, Thursday, Friday one week and Tuesday and Friday the next or if you preferred Thursday and a Tuesday or Friday. I understand that this is not the ideal solution, however this is the best solution at this time.

Thanks

Kellie

From: Maburuse, Zivai (Health)
Sent: Thursday, 9 February 2017 2:38 PM
To: Lahoria, Rajat (Health); Noffke, Kellie (Health)
Subject: RE: MS POSITION [SEC=UNCLASSIFIED]

Hi Rajat and Kellie,
If Marie starts at 12 and finish at 5 pm, her FTE will be over the 0.53, it will be better if she could start at 1pm and finish at 5pm, however this need Marie to agree to it as it is a non standard shift.
Kellie, how would you like us to progress this?

Kind regards

Zivai Maburuse
Ag Nurse Manager
Division of Medicine
Canberra Hospital & Health Services
Building 1, Level 6
Tel 62442657
[redacted]

From: Lahoria, Rajat (Health)
Sent: Thursday, 9 February 2017 2:23 PM
To: Maburuse, Zivai (Health)
Cc: Noffke, Kellie (Health)
Subject: RE: MS POSITION [SEC=UNCLASSIFIED]

Hi Zivai,

My session on Thursday is from 1:30 Pm to 5:00 Pm and I don't mind if she starts at 12:00 as long as there is reasonable overlap for us to work together for some time. It should be every Thursday as there is a lot of work generated from MS clinics each week that needs to be taken care of.

Thanks,
Rajat

From: Maburuse, Zivai (Health)
Sent: Thursday, 9 February 2017 2:04 PM
To: Lahoria, Rajat (Health)
Cc: Noffke, Kellie (Health)
Subject: MS POSITION [SEC=UNCLASSIFIED]

Hi Rajat,
What time would you like Marie to start on Thursdays afternoon and is it only 2 Thursdays per month.

Kind regards

Zivai Maburuse
Ag Nurse Manager
Division of Medicine
Canberra Hospital & Health Services
Building 1, Level 6
Tel 62442657
[redacted]

Noffke, Kellie (Health)

From: Lahoria, Rajat (Health)
Sent: Thursday, 9 February 2017 12:50
To: Maburuse, Zivai (Health)
Cc: Noffke, Kellie (Health)
Subject: Re: MS Nurse FTE [SEC=UNCLASSIFIED]

Many thanks Zivai!
Rajat

Sent from my iPhone

On Feb 9, 2017, at 12:27 PM, Maburuse, Zivai (Health) <Zivai.Maburuse@act.gov.au> wrote:

> Hi Rajat,
> I will discuss with Kellie and see how we can roster Marie
>
> Kind regards
>
> Zivai Maburuse
> Ag Nurse Manager
> Division of Medicine
> Canberra Hospital & Health Services
> Building 1, Level 6
> Tel 62442657
> [redacted]

From: Lahoria, Rajat (Health)
Sent: Thursday, 9 February 2017 12:09 PM
To: Maburuse, Zivai (Health)
Cc: Noffke, Kellie (Health); Lueck, Christian (Health); McMaster, Kathryn (Health)
Subject: MS Nurse FTE

Dear Zivai,

My understanding is that the MS nurse appointment is for 0.5 FTE. Which would mean that Marie should be available to work in this capacity for 2.5 days per week. As you would agree that the role of MS nurse is also to return patient phone calls and messages, organise treatments and assist with other aspects of their management in the community in addition to running the MS clinic, we must ensure that Marie has sufficient time to take care of these other responsibilities.

May I suggest that in addition to Tuesdays and Fridays she is also available to work in the capacity of MS nurse on Thursday afternoon. This would mirror my schedule. Eventually I would be flexible for her to work on any another day which is most most suitable for her and the 7A roster. As for now she is completely dependent on me to educate her how to carry out these jobs. As I have administrative time of alternate Thursday afternoons it is the best time for me sit with her and go through the job list. Otherwise it would put an extra strain on me to find time on Tuesday and Friday afternoons when I also have other responsibilities including ward rounds.

I would be interested to hear your thoughts.

Many thanks,
Rajat

Noffke, Kellie (Health)

From: Lahoria, Rajat (Health)
Sent: Tuesday, 24 January 2017 17:19
To: McFarlane, Helen (Health)
Cc: Noffke, Kellie (Health); Lueck, Christian (Health); Gallagher, Clare (Health)
Subject: Re: MS Nurse clinic space [SEC=UNCLASSIFIED]

Thanks, Helen!
Regards,
Rajat

Sent from my iPhone

On Jan 24, 2017, at 5:14 PM, McFarlane, Helen (Health) <Helen.McFarlane@act.gov.au> wrote:

> Hello Rajat,
> Thank you for your e-mail.
> We will see what we can source regarding possible available computer /phone for Marie within Brett's office.
>
> Kind regards,
> Helen
>
> <image001.jpg> <image002.jpg>
>
> **Helen McFarlane** | Acting Clinical Nurse Consultant/ Nurse Manager
> Chronic Care Program | Canberra Hospital & Health Services
> **P** +612 6174 5289 [redacted]
> **A** Building 1 Level 8A | PO Box 11 WODEN ACT 2606
> **E** helen.mcfarlane@act.gov.au **W** www.health.act.gov.au

---

From: Lahoria, Rajat (Health)
Sent: Tuesday, 24 January 2017 12:23 PM
To: McFarlane, Helen (Health)
Cc: Noffke, Kellie (Health); Lueck, Christian (Health); Gallagher, Clare (Health)
Subject: RE: MS Nurse clinic space [SEC=UNCLASSIFIED]

Dear Helen,

Marie started her MS duties today and we just did a clinic together. My understanding is that she will share the office with Brett on level 7 main building. She will also need a computer and phone for her office. I'm not entirely sure how to go about it. Could someone please advise?

Many thanks,
Rajat

From: McFarlane, Helen (Health)
Sent: Tuesday 17 January 2017 15:37
To: Lahoria, Rajat (Health)

Cc: Noffke, Kellie (Health); Lueck, Christian (Health); Gallagher, Clare (Health)
Subject: FW: MS Nurse clinic space [SEC=UNCLASSIFIED]

Good afternoon Rajat,
As an update as to where we are at with training for Marie.
I had difficulty in making contact with [redacted] in Sydney and have only just managed to talk with her today.

[redacted] is on leave currently but will be commencing his MS clinic in February and I have asked [redacted] to e-mail me some coming dates of clinics that will provide Marie with a lot of exposure to the patients.
The clinics are held on Wednesdays only and so [redacted] thinks it best that Marie attends 2 or perhaps 3 Wednesdays in Sydney with them depending on how comfortable she becomes with her knowledge and skills etc.

As we move to arrange this would it be plausible for Marie to accompany yourself during your Tuesday/Friday MS clinics in the coming weeks?
I can then liaise with Kellie to see if Marie can be released from her roster on appropriate days.

Kind regards,
Helen

<image001.jpg> <image002.jpg>

Helen McFarlane | Acting Clinical Nurse Consultant/ Nurse Manager
Chronic Care Program | Canberra Hospital & Health Services
P +612 6174 5289 [redacted]
A Building 1 Level 8A | PO Box 11 WODEN ACT 2606
E helen.mcfarlane@act.gov.au **W** www.health.act.gov.au

From: McFarlane, Helen (Health)
Sent: Thursday, 8 December 2016 11:30 AM
To: Lahoria, Rajat (Health)
Subject: RE: MS Nurse clinic space [SEC=UNCLASSIFIED]

Good morning Rajat,
Would be able to confirm the times you would like Marie to have clinic space in central outpatients please.
Are you happy for it to mirror the times you are there i.e Tuesday and Friday mornings from 8:30 to 12pm?
I understand that every 4 weeks you do not have clinic on the Tuesday morning.

I will then make a more formal and detailed request to Anne Douglas CNC Outpatients so that we can get it actioned ASAP.

Kind regards,
Helen

<image001.jpg> <image002.jpg>

Helen McFarlane | Acting Clinical Nurse Consultant/ Nurse Manager
Chronic Care Program | Canberra Hospital & Health Services
P +612 6174 5289 [redacted]
A Building 1 Level 8A | PO Box 11 WODEN ACT 2606
E helen.mcfarlane@act.gov.au **W** www.health.act.gov.au

From: Lahoria, Rajat (Health)
Sent: Wednesday, 7 December 2016 12:38 PM
To: McFarlane, Helen (Health); Noffke, Kellie (Health)
Cc: Lueck, Christian (Health); Gallagher, Clare (Health)
Subject: RE: MS Nurse clinic space [SEC=UNCLASSIFIED]

Dear Helen and Kellie,

I have now spoken to BMRI and the director of MS clinic is happy to support Marie's training through their clinic. This can be organised by liasing with [redacted] the MS CNC at BMRI. Her email is [redacted]

[redacted] has also highly recommened that Marie attends MSNA conference next year which I believe will take place in Tasmania.

They have also recommened online education material which I will forward to Marie.

Please let me know if I could assist in anyway in moving things forward.

Kind regards,
Rajat

From: Lahoria, Rajat (Health)
Sent: Wednesday, 30 November 2016 7:18 PM
To: Noffke, Kellie (Health); McFarlane, Helen (Health)
Cc: Lueck, Christian (Health); Gallagher, Clare (Health)
Subject: RE: MS Nurse clinic space [SEC=UNCLASSIFIED]

Many thanks Helen and Kellie.

We plan to send Marie to the MS clinic at Brain and Mind Research Insitutute (BMRI) in Camperdown, NSW. The name of the MS nurse there is [redacted] but it would be best if Christian and I discuss this possibility with the Director of the clinic. I hope they will be agreeable. Once I hear back from him I will let you know.

Thanks you again for your help.

Kind regards,
Rajat

From: Noffke, Kellie (Health)
Sent: Wednesday 30 November 2016 09:20
To: McFarlane, Helen (Health)
Cc: Lahoria, Rajat (Health); Lueck, Christian (Health); Gallagher, Clare (Health)
Subject: RE: MS Nurse clinic space [SEC=UNCLASSIFIED]