

# Minutes

## National Renal Transplant Leadership Team Meeting Operational Group

**Date:** 29 March 2019

**Time:** 9.45 am – 3.00 pm

**Location:** Ministry of Health, 133 Molesworth Street, Wellington

<b>Attendees:</b>	Nick Cross (Chair)	Renal physician	CDHB
	Ian Dittmer	Renal physician	ADHB
	Jane Potiki	Principal advisor	MoH
	Jane Presto	Operations manager representative	CCDHB
	John Irvine	Renal physician	CDHB
	John Schollum	Renal physician	SDHB
	Kristin Wilson	Business manager LTU	ADHB
	Philip Matheson	Renal physician	CCDHB
	Ralph La salle	Team leader Planning & Funding	CDHB
	Claire Beckett	Transplant coordinator	CCDHB
	Stephen Munn	Transplant surgeon	ADHB
	Sue Townsend	Minutes	CDHB

<b>Apologies:</b>	Justin Roake	Transplant surgeon	CDHB
	Denise Beechey	Renal CNS	CMDHB
	Dilip Naik	Transplant surgeon	CCDHB
	Ralph La salle (lateness)	Team leader Planning & Funding	CDHB

Agenda item	Discussion
1. Meeting opened & introductions	<ul style="list-style-type: none"> <li>Introduction of Sue Townsend CDHB – replacing Colette Meehan as minute secretary and support to Nick Cross.</li> <li>Nick expressed his thanks for the support shown by colleagues around the country and particularly the CCDHB team, for the transplantation of a Canterbury DHB patient in Wellington in the week following the terror attacks of 15 March in Christchurch</li> </ul>
2. Conflict of interest	<ul style="list-style-type: none"> <li>COI forms received from Stephen Munn and Claire Beckett.</li> </ul>
3. Minutes of NRTL Strategic group Feb 2019 (for noting)	<ul style="list-style-type: none"> <li>Tabled and noted – no comments.</li> </ul>

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4. Actions register	<ul style="list-style-type: none"> <li>• Purpose – to keep group members informed, the register is disseminated prior to each meeting with actions taken shown as tracked changes, a finalised version is sent out afterwards.</li> <li>• Item 9 – DHB supporting = domicile of resident, funding group generally supportive and able to see benefit. Sticking point is the length of time overseas donors need to stay in New Zealand. Important that these donors have as much work up done as possible prior to arrival in New Zealand.</li> <li>• Mapping document – this is nearly finished and will be circulated next week.</li> <li>• Discussion on item 18 – after consideration will be closed at this time.</li> </ul> <p><b><u>ACTION POINTS:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Nick to circulate mapping document next week.</b></li> <li>• <b>Sue to close item 18.</b></li> </ul>
4a. Correspondence	<ul style="list-style-type: none"> <li>• Emails have been sent out re updated policies – reminder to be added to Suetonia’s newsletter (ANZSN circular).</li> </ul> <p><b><u>ACTION POINT:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Nick.</b></li> </ul>
5. CD update	<ul style="list-style-type: none"> <li>• Nick attended the Organ Transplant Authority (OTA) conference in Sydney, March 2019.</li> <li>• He spoke on live donor initiatives in NZ and consistencies in access to kidney transplantation.</li> <li>• OTA is concerned that transplanters are not unified and moving in a single direction – would like to have better communication and oversight on processes.</li> <li>• Conference was 70% about donation and was mostly attended by donation experts.</li> <li>• ODNZ is understood to be concerned about planned establishment of a transplant authority in NZ.</li> <li>• Nick has been invited to speak at the ODNZ study day.</li> <li>• The number of deceased donors has increased.</li> <li>• Work on metrics continues.</li> </ul>
6. Biopsy process for deceased donor kidneys	<ul style="list-style-type: none"> <li>• Christchurch case notified by Justin and John I.</li> <li>• At the time of retrieval wedge biopsy led to requirement for additional surgery firstly for a haematoma and secondly for a large bleed. Both were identified as coming from the biopsy site.</li> <li>• Substantial delay was also apparent with the kidney delivery to Christchurch being delayed until late morning.</li> <li>• Core and wedge biopsies can both result in bleeding, but this is usually easily controlled.</li> <li>• Other countries perform fewer biopsies than is the practice in NZ.</li> <li>• It was agreed that it would unwise to alter the protocol on the basis of a single case.</li> <li>• Work is underway in Auckland (Dr Dittmer and registrar) to audit outcomes of biopsies in deceased donation</li> <li>• There is potential for long cold ischaemic time due to kidneys and biopsies being sent to Auckland, but it is best for reporting to continue to be done in Auckland due to lower case numbers and consequent lack of relevant pathology experience in other centres. .</li> </ul>

Agenda item	Discussion
	<ul style="list-style-type: none"> <li>• Delivery of biopsy samples to the lab is occasionally an issue (although not necessarily in this case), as the tissue can be sent via Lamson tube – delivery by hand may be preferable.</li> </ul> <p><b><u>ACTION POINTS:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Nick will discuss delivery protocol with ODNZ.</b></li> <li>• <b>Ian to report back ? May with results of biopsy audit.</b></li> </ul>
7. TSANZ report & representation	<ul style="list-style-type: none"> <li>• TSANZ covers all solid organ donation and is responsible for generating clinical guidelines.</li> <li>• Helen Pilmore will be President Elect from July 2019, but as such will not be ordinary NZ representative.</li> <li>• Constitution allows for 1 NZ representative – councillors serve a 4 year term and Nick’s term finishes in July. This raises the issue of how we relate to TSANZ after July, especially if the NZ representative is not renal.</li> <li>• No NZ representative stood for election to council as ordinary representative.</li> <li>• At the last meeting Nick was asked to stay on the council ex officio – he is willing to do so but will only be able to attend approximately 1 meeting per year.</li> <li>• President elect Helen Pilmore could become part of NRTLTL – she is to be invited to the next strategy group meeting.</li> <li>• TTS meeting in 2024 – Ian has suggested Auckland as venue, and Nick put this to TSANZ council.</li> </ul> <p><b><u>ACTION POINT:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Helen to be invited to next strategy group meeting – Sue to add to agenda.</b></li> </ul>
8. NTA process	<ul style="list-style-type: none"> <li>• Kristin raised the issue of patients from outside Auckland DHB requiring accommodation for 6 weeks post discharge and referring DHBs not prepared to pay any more than standard NTA contribution of \$100/night. Currently not possible to find accommodation in Auckland for &lt; \$200/night.</li> <li>• Lack of suitable accommodation may delay discharge.</li> <li>• NTA review has highlighted inequalities but has not provided solutions.</li> <li>• There is variability in how DHBs interpret NTA policy and apply for exceptions so funding levels vary.</li> <li>• Donors are better served than recipients, but improving funding for recipient accommodation would set a precedent for other patient groups.</li> <li>• Kristin to advise Jane which DHBs fund at the minimum level.</li> <li>• ADHB has travel/accommodation officer for heart/lung and liver transplant patients, but not for kidney – this means T&amp;A is regarded as the patient’s responsibility with NTA payment as a reimbursement.</li> <li>• Jane noted that MoH can write to DHBs to highlight issues but cannot be directive.</li> <li>• Is length of patient stay related to level of support provided? ADHB appears to have the longest average duration of stay post transplant.</li> <li>• Longest stay has been 44 days (35 year old patient) at ADHB.</li> <li>• This issue needs to be raised with Transplant Board again.</li> </ul>

Agenda item	Discussion
	<p><b><u>ACTION POINTS:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Kristin to advise Jane which DHBs pay minimum only.</b></li> <li>• <b>Jane to examine any relationship between length of stay for each DHB of domicile and funding provided via NTA Jane and Nick to write to funders re variance in approach (show to others on NRTLTL first).</b></li> </ul>
10. Projections of activity for transplant centres	<ul style="list-style-type: none"> <li>• Overall steady increase in the number of transplants per year, with Canterbury ahead of target.</li> <li>• Goal is for each of the three transplant DHBs to be transplanting at the same rate by the end of 2021/22 based on the rate of ESKD in the DHBs they serve.</li> <li>• Goal rates are 423 transplants per 1,000 patients, and 181 live donor transplants per 1,000 incident patients.</li> <li>• A letter has been drafted to go out to referring DHBs with a quality improvement resource requesting they improve referrals and provide increased resourcing/funding for assessments of donors and recipients – this will go to CEs, CDs and funders, and needs to include DHBs without renal departments. Each letter to contain a tailored paragraph.</li> <li>• The waiting list is diminishing – if maintained, criteria for access should be reassessed.</li> <li>• Reduction in outcomes may be an effect of any increase in marginal patients being transplanted.</li> </ul> <p><b><u>ACTION POINTS:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Stephen to send Ernst &amp; Young report to Nick for purposes of comparison (requested by Sue via email 10/04/2019).</b></li> <li>• <b>Nick to write tailored paragraphs for inclusion in letter to DHBs.</b></li> </ul>
12. Hepatitis C positive donor study	<ul style="list-style-type: none"> <li>• TSANZ has updated guidelines on viral positive donors.</li> <li>• Five year observational study (novel treatment protocol) proposed by John S – protocol has been written but still needs input from hepatologist and ODNZ..</li> <li>• Protocol is simplified version of Australian protocol – some exclusions removed, end points simplified.</li> <li>• Ethics application is underway – study is classified as innovative treatment.</li> <li>• NRTLTL to provide oversight – DSMC not required.</li> <li>• Informal pre consent for Hep C transplantation is best done in clinic than by letter – patients to receive an information sheet prior to written informed consent.</li> </ul> <p><b><u>ACTION POINT:</u></b></p> <ul style="list-style-type: none"> <li>• <b>John S to circulate final versions of protocol and consent form.</b></li> </ul>
9. Cardiac testing at Waikato & Lakes DHBs	<ul style="list-style-type: none"> <li>• Drew H joined via phone.</li> <li>• Substantial delays for myocardial perfusion studies described</li> <li>• Outsourcing has been considered but financing this is an issue – ADHB have outsourced at times when needed.</li> <li>• Stress echo service currently not operating but solutions being sought – CTA can be used in nondiabetics, Drew to discuss with imaging cardiologists, engage with ARTG about reducing requirements for testing.</li> </ul>

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13. Donation & transplantation agency / NZBS	<ul style="list-style-type: none"> <li>• Act in progress allowing NZ Blood Service to become the national agency for organ donation and transplantation in New Zealand – they would oversee implementation of the strategy to increase deceased donation rate.</li> <li>• Work planned at MOH for implementation</li> <li>• Act does not specify scope (ie whether encompasses NRTLTL activity or not)– this will need to be established.</li> <li>• Act is due for first reading in April, then goes to health select committee to be put out for public submissions – NRTLTL will send in a submission.</li> <li>• MoH will then summarise before second and third readings.</li> <li>• Once enacted an implementation date will be set.</li> <li>• Health and Disability Act will also be amended – compensation is currently as an issue as it states that both parties are compensated if both surgeries are performed in New Zealand. Unclear what NZ's compensation responsibilities would be where this is not the case.</li> <li>• NRTLTL needs to engage with BNZ – Nick has had a phone meeting with Sam Cliffe (CEO) and Christine van Tilburg (Director Business Improvement &amp; Partnerships).</li> <li>• All present in favour of NZBS taking on this role.</li> </ul>
14. VSEAC	<ul style="list-style-type: none"> <li>• Vigilance and Surveillance Expert Advisory Group is part of OTA and was set up in 2017.</li> <li>• At present in NZ we track adverse events at the local M&amp;M level but there is no national level collection of data on transplant outcomes.</li> <li>• Under VSEAC adverse events are reported online then reviewed by the VSEAC committee using a consequence/recurrence probability matrix. Red, yellow and green notices are sent out to submitters.</li> <li>• As we will be receiving Australian organs it makes sense for us to contribute to VSEAC.</li> <li>• NZ could start by gaining access to VSEAC reports, then to start contributing data, and finally to contribute to the feedback process.</li> </ul> <p><b><u>ACTION POINT:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Nick to contact VSEAC to request access to reports (done).</b></li> </ul>
15. TTS	<ul style="list-style-type: none"> <li>• Ian had engaged with TTS reps who were in NZ recently.</li> <li>• TTS have reviewed the new conference centre in Auckland and were impressed with it.</li> <li>• A bid to host TTS will be compiled and needs to be submitted soon.</li> <li>• TSANZ 2021 will also be in New Zealand - potentially Christchurch or Queenstown.</li> </ul>
17. ANZKX	<ul style="list-style-type: none"> <li>• New Zealand should maintain three centres within the exchange.</li> <li>• Auckland will be the receiving city as Australian centres will not ship on any route with only one flight per day.</li> <li>• John I and Ian will be on the allocation committee – this has not yet been ratified by RTAC.</li> <li>• Jane will submit a briefing to the Minister of Health with information to come from Ian.</li> </ul> <p><b><u>ACTION POINTS:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Ian to send information to Jane.</b></li> <li>• <b>Jane to submit briefing to Minister.</b></li> </ul>

Agenda item	Discussion
18. Waiting list error checking process	<ul style="list-style-type: none"> <li>• NZKAS information contains errors occasionally, mainly due to human/communication factors</li> <li>• Coordinators at referring centres are best placed to be responsible for monitoring the accuracy of their waiting lists – a report is sent out to them in the second half of each month and they are to check against the previous report plus current information at their unit, then respond with any errors to be corrected.</li> <li>• Format, form of report reviewed and confirmed.</li> <li>• Jane will discuss with MoH IT service re the best method for sending these reports – possibilities are secure file transfer or locked spreadsheet.</li> <li>• Locked spreadsheet is acceptable.</li> </ul> <p><b><u>ACTION POINTS:</u></b></p> <ul style="list-style-type: none"> <li>• <b>Jane to provide communication guidance to Heather (via Nick).</b></li> <li>• <b>Heather to confirm production of report and dissemination in line with MOH guidance.</b></li> <li>• <b>Nick then to contact all coords and CDs about new process.</b></li> </ul>
19. Other business	<ul style="list-style-type: none"> <li>• TSANZ viral screening guidelines – nucleic acid testing (HIV/HBV/HCV) at point of deceased donation will be recommended. Agreed this was appropriate in NZ. Ian will ask NZBS to implement.</li> <li>• Communication of policy changes – policy changes will be discussed at a group meeting, draft changes approved, then documents uploaded to MoH website. Chair will then send email notification to CDs / coordinators / NRTLTL.</li> <li>• Jane is looking for Maori case studies illustrating access issues/methods of overcoming these (one donor / one recipient) for a presentation. Please contact her if you have any appropriate patients.</li> </ul>
Meeting closed:	2.40 pm
Next meeting:	Strategic group – 24 May 2019 Sudima Hotel Christchurch Airport