

Minutes

Neurodevelopmental Disorders Steering Committee

Date:	23 rd August 2017
Time:	15:00
Venue:	Level 6 Boardroom, Centre for Children's Health Research
Chair:	Dr Geoff Wallace
Secretary:	Michael Carroll
Attendees:	Dr Andrew Hallahan (AH); Dr Helen Irving (HI); Dr Honey Heussler (HH); Michael Carroll (MC); Rochelle Greene (RG); Sonya Stacey (SS); Melissa Fox (MF); Greg Perry (GP)
Apologies:	Prof John Pearn; Emily Milburn

Item	Topics of discussion	Details of Discussion
1	Meeting opening: 15:05	
1.1	Welcome and apologies	GW welcomed attendees and noted apologies – see above.
1.2	Confirmation of previous minutes	The minutes of the previous meeting held on Wednesday 14 th June 2017 were confirmed as true and correct by MC
1.3	Business arising from the previous minutes	n/a
2	Standing agenda items	
2.1	CAS Update	<p>Status:</p> <ul style="list-style-type: none"> • Currently 29 children have passed the selection panel; 20 of whom are on Epidiolex • Some initial participants have now been on 3 months and will be reviewed and possibly withdrawn; first occurrences of this are this week • More Epidiolex stock on order • Update letters to current applicants are slightly overdue due to waiting on the Research Directorate website update. The letters will include the website as an information source. Discussed further at 3.2. <p>Results:</p> <ul style="list-style-type: none"> • One child showing sustained benefit • Other observations in speech and language improvements • Some other initial improvements have now relapsed • More detailed outcomes (e.g. efficacy, side effects) will be available early December <p>Other</p> <ul style="list-style-type: none"> • John Lawson (NSW CAS) data: no significant changes/improvements noted to date; some improvements in drop attacks for Dravet Syndrome children; N = 40; recently received product for 25 more participants; some participants have discontinued • QLD CAS differs from NSW with respect to doing video EEGs • South Australia and Western Australia are the only states not doing trials

Item	Topics of discussion	Details of Discussion
s.73 - Irrelevant information (2.2)	s.73 - Irrelevant information (2.2) update	<p>Study (Commercial)</p> <ul style="list-style-type: none"> Of the 6 original participants from LCCH site: 3 are continuing in Phase 1; one has progressed to Phase 2; 2 have recently been withdrawn due to unfavourable skin reactions to the gel Outcomes to date appear good: noticeable increases in confidence; better ability to approach people Still waiting on GW input re one-page proposals. See 3.3 below.
3a	Matters for discussion	
3.1	Review of Steering Committee membership	<ul style="list-style-type: none"> Focus of Steering Committee to be re-aligned from to the CAS to the CCTRND MC asked for thoughts on changes to membership? HI recommended distributing the draft Terms of Reference; decisions on changing membership can then follow
3.2	Establishment of the Centre for Clinical Trials in Rare Neurodevelopmental Disorders (CCTRND)	<ul style="list-style-type: none"> CCTRND will have its first web presence when the Research Directorate website is updated. This update has experienced a number of delays which are now impacting on research agenda development, communications with CAS participants, and the promotion of the CCTRND in general. Request that AH assist in getting the update completed. Finances: splitting of funds into separate CAS and Research cost centres is near complete and should be visible on DSS soon; funding available at present is considerable; while expenditure has increased considerably with a number of new roles, use of funds needs to be discussed in further within the Steering Committee Staffing: CAS nurse (Michelle Lewis) has started and fitting in very well; offers for the two Senior Research Officer positions are about to be made; interviewing for the Psychologist is continuing next week Other items, such as purchasing, to be discussed at a later date
3.3	Centre research agenda	<ul style="list-style-type: none"> Need to ensure the research we conduct is in line with the MoU between the Government and GW Pharma and any other requirements Severe autism study: for severely disabled children with challenging behaviours. Further discussion needed with GW Pharma to progress this idea. MC and GP to discuss this further with GW Pharma at teleconference later today. Development of agenda continuing; to be included on the CCTRND website (within the Research Directorate) when possible
3.4	Research proposals received by the Centre	<ul style="list-style-type: none"> We have been in touch with LCCH groups (e.g. Neurology; Metabolics) to introduce the idea that we may be able to provide some support to their research ideas using our resources What do we ask for in a research proposal, and how do we determine what type and amount of support/resources go to which proposals? Ideally, given our funding is only until mid-2019, would like to avoid a protracted process. Also, giving out considerable dollar amounts to support employing multiple staff is not sustainable and unlikely to be feasible given time constraints. HH: we could provide support to working this resource up, such as providing admin support or assisting in the collection of pilot data to support going for grants Independent review process required Steering Committee agreed that objective independent proposal review is needed. MC to draft a review process and distribute it to committee members for comment
3.5	Access to non-trial cannabinoids	<ul style="list-style-type: none"> Patient requests for cannabinoids, such as in palliative care and neurology; how as an organisation do we manage those requests? GP: Brain and Mind Centre at The University of Sydney is a good contact Possibly need to create another panel to review cases HI to follow up further with AH, particularly around what products are / will be available HI: also had possible research idea relating to palliative care and cerebral palsy. For further discussion when more time is available.

Item	Topics of discussion	Details of Discussion
3b	Matters for noting	
	n/a	n/a
4	Action List	
4.1	<ul style="list-style-type: none"> MC: email draft Terms of Reference to Steering Committee members 	
4.2	<ul style="list-style-type: none"> AH: follow up on when the release of the new Research Directorate website will occur 	
4.3	<ul style="list-style-type: none"> MC & GP: discuss with GW at upcoming teleconference research proposal content required; relay on to HH asap 	
4.4	<ul style="list-style-type: none"> MC: draft research proposal review process and distribute 	
4.5	<ul style="list-style-type: none"> HI: to follow up with AH regarding access to non-trial cannabinoids 	
5	For information	
	n/a	
6	Meeting close: 16:20	
	Next Meeting: 4pm Wednesday, 20 September 2017, Level 6 Boardroom, CCHR	

RTI Release

Terms of Reference

Centre for Clinical Trials in Rare Neurodevelopmental Disorders (CCTRND) Steering Committee

1. Purpose

The purpose of the Centre for Clinical Trials in Rare Neurodevelopmental Disorders' (CCTRND) Steering Committee is to:

- Agree on clinical trial protocols and necessary governance arrangements to facilitate Queensland's participation in trials related to medicinal cannabis and/or rare neurodevelopmental disorders;
- Facilitate Queensland's Medicinal Cannabis Compassionate Access Scheme (CAS) for children with severe drug-resistant epilepsy;
- Communicate updates to key stakeholders and other interested parties and the general public;
- Support the General Manager Operations in meeting responsibilities outlined in The Public Service Act 2008, The Health Services Act 2011 and other relevant legislation;
- Support the Hospital and Health Board in meeting their responsibilities outlined in the *Hospital and Health Boards Act 2011* and the Service Agreement for Children's Health Queensland; and
- Set an example of high functioning team behaviours and a culture of performance through the effective conduct and management of committee functions and member interactions.

2. Functions

The function of the CCTRND Steering Committee is to:

- Oversee the implementation of agreed research design;
- Provide guidance to ensure the research is conducted responsibly, ethically and in the interests of the wider community;
- Oversee the development of the local research procedures and processes to ensure: appropriate governance and reporting processes are in place;
- Contribute to the efficiency and effectiveness of the research;
- Bring issues requiring clarification, discussion and/or resolution to the meeting based on their expertise and from the perspective of those they represent;
- Address issues of concern;
- Advise on communication and messages to all stakeholders;
- Maintain the integrity of the research project; and
- Maintain the confidentiality of the discussions of the Steering Committee and only release information as agreed by the Steering Committee.

Any conflict of interest will be declared prior to discussion of that matter at meetings and a register of conflicts of interest will be maintained by the secretariat.

3. Authority

The CCTRND Steering Committee:

- functions under the authority of the Health Service Chief Executive
- reports to the Children's Health Queensland Executive Leadership Team.

Decision making: Meeting recommendations are made by consensus. If consensus cannot be reached, the Chair reserves the right to make the final decision or to escalate the matter to the Executive Director Medical Services.

Committee members are individually accountable for their delegated responsibility and collectively responsible to contribute to advice provided by the Committee to the Chair in the interests of a whole-of-service position.

4. Frequency of meetings

Meetings will be held at least 12 times a year (more if required) and a schedule of meetings will be agreed in advance. In addition, the Chair may call additional meetings as necessary to address any matters referred to the committee or in respect of matters the committee wishes to pursue within its terms of reference.

5. Membership

- | | |
|---------------------------------------|---|
| ▪ Chair | Dr Geoff Wallace |
| ▪ Secretariat | Emily Milburn |
| ▪ CHQ Executive Sponsor | Dr Andrew Hallahan |
| ▪ Director of Research | Prof. John Pearn |
| ▪ Chair, CHQ Ethics & Law | Dr Helen Irving |
| ▪ Department of Health Representative | Greg Perry |
| ▪ Director of Pharmacy | Sonya Stacey |
| ▪ Neurodevelopmental Representatives | Dr Honey Heussler (Medical Director of Child Development) |
| | Michael Carroll (Clinical Research Manager) |
| ▪ Consumer Representative | Melissa Fox |

6. Reporting

The CCTRND Steering Committee provides the following:

- Minutes from the meeting to the relevant Executive committee monthly; and
- Meeting decisions and activity summary to relevant Executive committee monthly.

Issues unable to be resolved by the committee are escalated to the relevant Executive Committee.

7. Performance

The CCTRND Steering Committee will develop an annual operational plan linked to organisational objectives and committee functions. The work plan will detail the goals and strategies for the committee with each strategy linked to a Key Performance Indicator (KPI) and a measure.

The Meeting Chair will facilitate an annual evaluation of the meeting's performance against the meeting's annual operational plan and Terms of Reference. Members will be consulted as part of the evaluation process. The evaluation will inform a review, where required, of the meeting's Terms of Reference.

Specific evaluation activities include:

- achievement of KPIs as identified in the meeting annual work plan;
- self-assessment by the committee in undertaking designated meeting functions;
- attendance records;
- evaluation of committee administrative process timeframes and secretariat responsibilities; and
- annual assessment by key stakeholders of the role of the meeting and achievement of its function.

8. Guiding principles

The *Hospital and Health Boards Act 2011* provides a set of principles intended to guide achievement of the Act's objectives. These principles guide deliberations of the meeting to:

- the best interests of users of public sector health services should be the main consideration in all decisions and actions of this committee;
- there should be a commitment to ensuring quality and safety in the delivery of public sector health services;
- there should be responsiveness to the needs of users of public sector health services about the delivery of public sector health services;
- there should be collaboration with clinicians in planning, developing and delivering public sector health services;
- information about the delivery of public sector health services should be provided to the community in an open and transparent way;
- there should be commitment to ensuring that places at which public sector health services are delivered are places at which:
 - i. employees are free from bullying, harassment and discrimination; and
 - ii. employees are respected and diversity is embraced
- there should be openness to complaints from users of public sector health services and a focus on dealing with the complaints quickly and transparently;
- opportunities for research and development relevant to the delivery of public sector health services should be promoted; and
- opportunities for training and education relevant to the delivery of public sector health services should be promoted.

Document history

Version	Date	Changed by	Nature of amendment
0.1	25/08/2017	Michael Carroll	Terms of Reference for the CCTRND

Previous versions should be recorded and available for audit.

RTI Release

From: [Louise Harris](#)
To: [Gregory Perry](#)
Cc: [Oliver Knott](#)
Subject: RE: next order
Date: Wednesday, 23 August 2017 5:21:09 PM

Hi Greg,

Sorry Julie noticed the address on the original order – when you write the new one can you put links address on it rather than the central pharmacy address?

Thank you,

Louise Harris | IPS Programme Manager



G-Pharm

Kent Science Park, Sittingbourne, Kent, ME9 8AG, UK



Upcoming OOO:

UK BH – Mon 28th Aug 2017

Fri 1st Sep 2017

Wed 13th – Fri 15th Sep 2017 (inc.)

Upcoming BH:

28th Aug 2017

From: Oliver Knott
Sent: 23 August 2017 07:59
To: Louise Harris
Subject: FW: next order

From: Gregory Perry [<mailto:Gregory.Perry@health.qld.gov.au>]
Sent: 07 July 2017 00:55
To: Louise Harris
Cc: Oliver Knott
Subject: next order

Hi Louise

we are looking to reorder Epidiolex – just need to determine quantity.

I have sent a draft order – I have left the quantity the same as last time.

I have spoken to link healthcare and they will move to arrange import permits x 2 once we have determined quantity.

I have spoken to Graham Cook at Central Pharmacy and he advises we still have about half the

original stock – this use will escalate over the next few months as we reach our patient numbers limit

Rochelle Green the pharmacist at CHQ asked that we do not over order due to expiry concerns

Kind regards

Greg



Gregory Perry

Director
Medicinal Cannabis Unit
Chief Medical Officer and Healthcare Regulation Branch
Prevention Division, **Department of Health**

p: 07 3708 5316 m: [redacted]
a: Locked Bag 21, Fortitude Valley BC QLD 4006
w: [Queensland Health](#) | e: Gregory.Perry@health.qld.gov.au



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RTI Release

From: Michael Carroll
To: Geoff Wallace; Gregory Perry; Honey Heussler; Melissa Fox; Andrew Hallahan; CHO EDMS; Rochelle Green; Helen Irving; Sonya Stacey; Michael Carroll; John Pearn [redacted]@uq.edu.au> [redacted]@uq.edu.au
Cc: John Pearn [redacted]@uq.edu.au> [redacted]@uq.edu.au); Emily Milburn
Subject: Neurodevelopmental Disorders Steering Committee meeting, 3pm today
Date: Wednesday, 23 August 2017 9:40:05 AM
Attachments: [image001.png](#)
[image002.png](#)
[image003.png](#)
[image004.png](#)
[image005.png](#)
[ND Steering Committee Meeting Agenda #16 - 23 August 2017.pdf](#)
[ND Steering Committee Meeting Minutes #14 - 14.06.17.pdf](#)

Hi everyone,

Attached is the agenda for today's Neurodevelopmental Disorders Steering Committee meeting **at 3pm**. Also attached are the minutes from the previous meeting. You'll note that they are from meeting #14... #15 scheduled for July 19 was cancelled at the last minute. I'll bring print outs of both documents to the meeting.

Please also note that Emily is currently out of the office so direct any email replies to me.

Kind regards,

Michael Carroll

Clinical Research Manager (Neurodevelopmental Disorders)

Children's Health Queensland Hospital and Health Service

Level 6 – Centre for Children's Health Research

Lady Cilento Children's Hospital

62 Graham Street, South Brisbane QLD 4101

T: 07 3069 7405 M: [redacted]

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W: www.childrens.health.qld.gov.au



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RELEASED

Agenda

Neurodevelopmental Disorders Steering Committee

Date: Wednesday, 23rd August 2017

Time: 3:00pm

Venue: Level 6 Boardroom, Centre for Children's Health Research

Apologies: Prof John Pearn; Emily Milburn

No	Item	Attachment	Time	Resp. officer
1	Meeting opening			
1.1	Welcome and apologies			GW
1.2	Confirmation of the previous minutes			GW
1.3	Business arising from the previous minutes			All
2	Standing agenda items			
2.2	CAS Update			GW & MC
s.73 - Irrelevant information (commercially sensitive)	2.3 Relevant information & Other Projects Update			HH
3	Matters for discussion			
3.1	Review of Steering Committee membership			MC
3.2	Establishment of the Centre for Clinical Trials in Rare Neurodevelopmental Disorders			MC
3.3	The Centre research agenda			MC
3.4	Discussion about research proposals received by the Centre			MC
3.5	Access to non-trial cannabinoids			HI
4	Matters for noting			
4.1				
5	For information			
5.1				
6	Meeting close			

Minutes

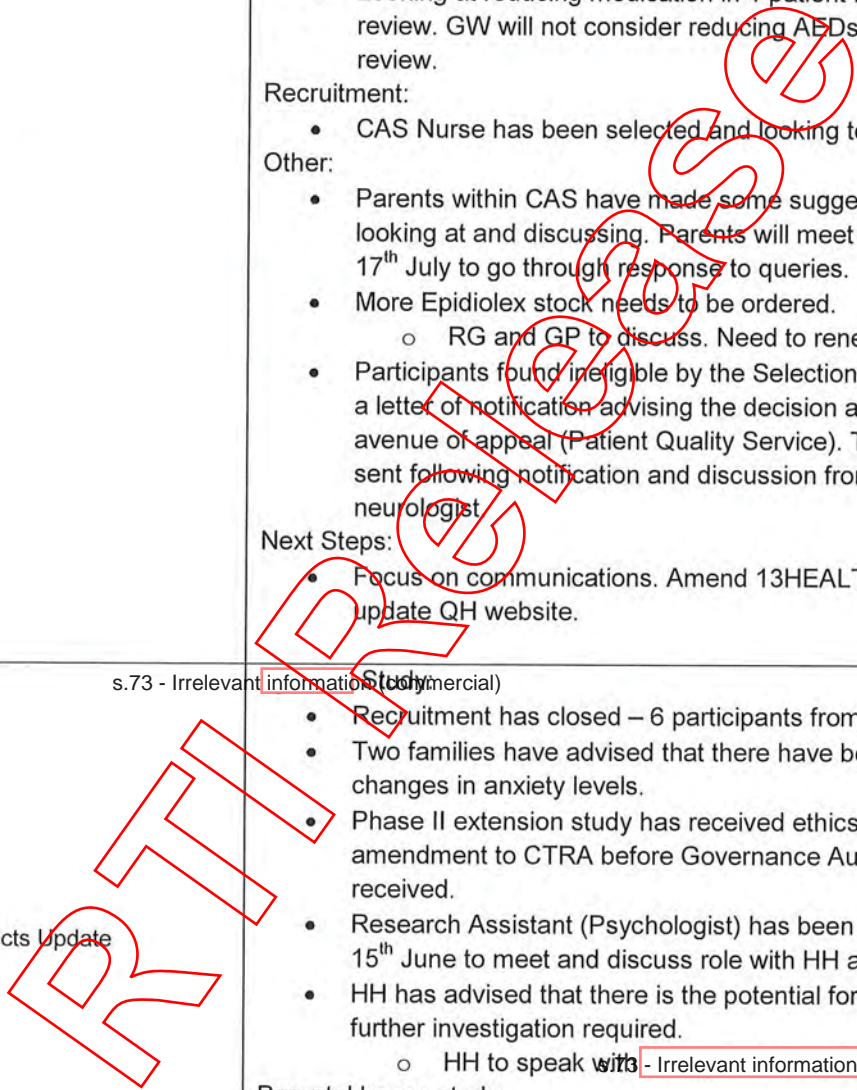
Neurodevelopmental Disorders Steering Committee

Date:	14 th June 2017
Time:	4:00pm
Venue:	Room 601, Level 6, Centre for Children's Health Research
Chair:	Dr Geoff Wallace
Secretary:	Emily Milburn
Attendees:	Dr Honey Heussler (HH); Prof Stephen Greene (SG); Michael Carroll (MC); Rochelle Greene (RG); Melissa Fox (MF); Greg Perry (GP);
Apologies:	Dr Andrew Hallahan (AH); Dr Helen Irving (HI);

Item	Topics of discussion	Details of Discussion
1	Meeting opening	
1.1	Welcome and apologies	Geoff welcomed attendees and noted apologies – see above.
1.2	Confirmation of previous minutes	The minutes of the previous meeting held on Wednesday 17 th May 2017 were confirmed as true and correct.
2	Discussion	

RTI RELEASES

<p>2.1</p>	<p>CAS Update</p>	<p>Status:</p> <ul style="list-style-type: none"> • Currently 11 kids on Epidiolex • Selection panel has reviewed 50 cases – 26 have been approved. A waiting list will be developed once we reach our 30 participant limit. <p>Results:</p> <ul style="list-style-type: none"> • General feeling from families has been positive; good responses in terms of seizures and in general well-being (walking where previously did not; communication improvements). Nobody is seizure free. QOL is better and frequency of seizures is down. • Looking at reducing medication in 1 patient following 3 month review. GW will not consider reducing AEDs until after 3 month review. <p>Recruitment:</p> <ul style="list-style-type: none"> • CAS Nurse has been selected and looking to start 10th July. <p>Other:</p> <ul style="list-style-type: none"> • Parents within CAS have made some suggestions which we are looking at and discussing. Parents will meet with GW and MC on 17th July to go through response to queries. • More Epidiolex stock needs to be ordered. <ul style="list-style-type: none"> ○ RG and GP to discuss. Need to renew the import licence. • Participants found ineligible by the Selection Panel are being sent a letter of notification advising the decision and providing an avenue of appeal (Patient Quality Service). This letter is being sent following notification and discussion from the treating neurologist. <p>Next Steps:</p> <ul style="list-style-type: none"> • Focus on communications. Amend 13HEALTH message and update QH website.
<p>2.2</p>	<p>Honey's Projects Update</p>	<p>s.73 - Irrelevant information (commercial)</p> <p>Study:</p> <ul style="list-style-type: none"> • Recruitment has closed – 6 participants from LCCH site. • Two families have advised that there have been significant changes in anxiety levels. • Phase II extension study has received ethics approval. Awaiting amendment to CTRA before Governance Authorisation can be received. • Research Assistant (Psychologist) has been recruited. Coming in 15th June to meet and discuss role with HH and MC. • HH has advised that there is the potential for a cross over study – further investigation required. <ul style="list-style-type: none"> ○ HH to speak with s.73 - Irrelevant information (commercial) <p>Parental hopes study:</p> <ul style="list-style-type: none"> • Has received ethics and governance approval. <ul style="list-style-type: none"> ○ Minor amendment to include additional questions to questionnaire submitted to ethics.



2.3	Centre development	<ul style="list-style-type: none"> • Finance team has confirmed that the funding is being split across CAS and research - \$0.8m to CAS and \$1.2m to research. • Plan is to work towards launching Centre name in line with launch of research website. • Perhaps look at hosting an event once we have some of our studies going. <ul style="list-style-type: none"> ◦ SG suggested after August when the 30 CAS participants are on board and there are results from information (commercial)
2.4	Research agenda and staff recruitment	<ul style="list-style-type: none"> • HH has been in discussions about some other projects - <ul style="list-style-type: none"> ◦ MC drafting a letter/proposal to GW for 12th July telecom with ideas for future studies. • SG suggested we use the cannabis program to develop a model for n of 1 studies. We could undertake a precision medicine study. Give a broad range of patient's cannabis (pick a range of disorders) and measure where the effect occurs. <ul style="list-style-type: none"> ◦ GP suggested that GWP would view this very favourably.
3 New Business/Ongoing Actions		
3.1	<ul style="list-style-type: none"> • MC meeting with Neurology team next week to discuss research opportunities within the centre. 	
4 Action List		
4.1		
5 For information		
5.1	<ul style="list-style-type: none"> • Clinical forum with John Skerritt – 12th July. HH and GW to potentially attend. • Senior Research Officer positions (x2) have been advertised and will close on 22nd June. 	
Meeting concluded at 5:15pm		
Next Meeting: 4pm Wednesday, 12 July 2017, Level 6 Boardroom, CCHR		

RTI REQUEST

From: [Helen Irving](#)
To: [Emily Milburn](#); [Geoff Wallace](#); [Gregory Perry](#); [Honey Heussler](#); [Melissa Fox](#); [Andrew Hallahan](#); [CHO_EDMS](#); [Rochelle Green](#); [Sonya Stacey](#); [Michael Carroll](#); [John Pearn](#) <john.pearn@uq.edu.au> <john.pearn@uq.edu.au>
Subject: RE: Call for Agenda Items - Neurodevelopmental Disorders Steering Committee - 23rd August 2017
Date: Friday, 18 August 2017 12:25:51 PM

Thanks Emily

Could we add to the agenda:
Discussion about access to non-trial cannabinoids please

Thanks
Helen

From: Emily Milburn
Sent: Tuesday, 15 August 2017 10:39 AM
To: [Geoff Wallace](#); [Gregory Perry](#); [Honey Heussler](#); [Melissa Fox](#); [Andrew Hallahan](#); [CHQ_EDMS](#); [Rochelle Green](#); [Helen Irving](#); [Sonya Stacey](#); [Michael Carroll](#); [John Pearn](#) <john.pearn@uq.edu.au> <john.pearn@uq.edu.au>
Subject: Re: Call for Agenda Items - Neurodevelopmental Disorders Steering Committee - 23rd August 2017

Good Morning All,

If you have any items to add to the below for next week's meeting could you please forward them through by COB Friday 18th August.

- Review of Steering Committee membership
- Establishment of the Centre for Clinical Trials in Rare Neurodevelopmental Disorders
- The Centre research agenda
- Discussion about research proposals received by the Centre

***Please note that we have moved this meeting forward an hour to 3pm.**

3pm, Wednesday 23rd July 2017
Level 6 Boardroom
Centre for Children's Health Research
62 Graham Street, South Brisbane

Kind regards
Emily
Emily Milburn
Project Support Officer (Neurodevelopmental Disorders)

Children's Health Queensland Hospital and Health Service
Level 6 – Centre for Children's Health Research
Lady Cilento Children's Hospital Precinct
62 Graham Street, South Brisbane QLD 4101
T: 07 3069 7457
E: Emily.Milburn@health.qld.gov.au
W: www.childrens.health.qld.gov.au



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From: Dorothy Vicenzino
To: Gregory Perry
Subject: RE: Call for Agenda Items - Neurodevelopmental Disorders Steering Committee - 23rd August 2017
Date: Tuesday, 15 August 2017 2:17:26 PM

If you don't get enough to attend – need to reschedule...

From: Gregory Perry
Sent: Tuesday, 15 August 2017 2:12 PM
To: Dorothy Vicenzino
Subject: Fwd: Call for Agenda Items - Neurodevelopmental Disorders Steering Committee - 23rd August 2017

Sent from my iPhone

Begin forwarded message:

From: John Pearn [redacted]@uq.edu.au>
Date: 15 August 2017 at 2:06:50 pm AEST
To: Emily Milburn <Emily.Milburn@health.qld.gov.au>, Geoff Wallace <Geoff.Wallace@health.qld.gov.au>, Gregory Perry <Gregory.Perry@health.qld.gov.au>, Honey Heussler <H.Heussler@health.qld.gov.au>, Melissa Fox [redacted]@hcg.org.au>, Andrew Hallahan <Andrew.Hallahan@health.qld.gov.au>, CHQ_EDMS <CHQ_EDMS@health.qld.gov.au>, Rochelle Green <Rochelle.Green@health.qld.gov.au>, Helen Irving <Helen.Irving@health.qld.gov.au>, Sonya Stacey <Sonya.Stacey@health.qld.gov.au>, Michael Carroll <Michael.Carroll@health.qld.gov.au>
Subject: RE: Call for Agenda Items - Neurodevelopmental Disorders Steering Committee - 23rd August 2017

Dear Emily and all, apologies--- I am giving a research paper at the north Coast.
Every best wish,
John P.

Professor John Pearn
Emeritus, School of Medicine, University of Queensland
Senior Paediatrician, RCH
CCHR Building
Lady Cilento Children's Hospital
South Brisbane, Qld 4101
Australia
Ph: [redacted]

From: Emily Milburn [<mailto:Emily.Milburn@health.qld.gov.au>]
Sent: Tuesday, 15 August 2017 10:39 AM
To: Geoff Wallace <Geoff.Wallace@health.qld.gov.au>; Gregory Perry <Gregory.Perry@health.qld.gov.au>; Honey Heussler <H.Heussler@health.qld.gov.au>; Melissa Fox [redacted] <[\[redacted\]@hccq.org.au](mailto:[redacted]@hccq.org.au)>; Andrew Hallahan <Andrew.Hallahan@health.qld.gov.au>; CHQ_EDMS <CHQ_EDMS@health.qld.gov.au>; Rochelle Green <Rochelle.Green@health.qld.gov.au>; Helen Irving <Helen.Irving@health.qld.gov.au>; Sonya Stacey <Sonya.Stacey@health.qld.gov.au>; Michael Carroll <Michael.Carroll@health.qld.gov.au>; John Pearn [redacted] <[\[redacted\]@uq.edu.au](mailto:[redacted]@uq.edu.au)>
Subject: Re: Call for Agenda Items - Neurodevelopmental Disorders Steering Committee - 23rd August 2017

Good Morning All,

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- The Centre research agenda
- Discussion about research proposals received by the Centre

***Please note that we have moved this meeting forward an hour to 3pm.**

3pm, Wednesday 23rd July 2017
Level 6 Boardroom
Centre for Children's Health Research
62 Graham Street, South Brisbane

Kind regards
Emily
Emily Milburn
Project Support Officer (Neurodevelopmental Disorders)

Children's Health Queensland Hospital and Health Service
Level 6 – Centre for Children's Health Research
Lady Cilento Children's Hospital Precinct
62 Graham Street, South Brisbane QLD 4101
T: 07 3069 7457
E: Emily.Milburn@health.qld.gov.au
W: www.childrens.health.qld.gov.au



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RTI REQUEST

From: [Gregory Perry](mailto:Gregory.Perry@health.qld.gov.au)
To: [Tanya Bain](mailto:Tanya.Bain@health.qld.gov.au)
Subject: Fwd: Draft Minutes - Neurodevelopmental Disorders Steering Committee - 17th May 2017
Date: Friday, 19 May 2017 4:56:14 PM
Attachments: [image001.gif](#)
[ATT00001.htm](#)
[image002.gif](#)
[ATT00002.htm](#)
[ND Steering Committee Meeting Minutes Draft #13 - 17.05.17.doc](#)
[ATT00003.htm](#)

Sent from my iPhone

Begin forwarded message:

From: Emily Milburn <Emily.Milburn@health.qld.gov.au>
Date: 19 May 2017 at 12:01:02 pm AEST
To: Geoff Wallace <Geoff.Wallace@health.qld.gov.au>, Gregory Perry <Gregory.Perry@health.qld.gov.au>, Honey Heussler <H.Heussler@health.qld.gov.au>, Melissa Fox <Melissa.Fox@hcq.org.au>, Andrew Hallahan <Andrew.Hallahan@health.qld.gov.au>, CHQ_EDMS <CHQ_EDMS@health.qld.gov.au>, Rochelle Green <Rochelle.Green@health.qld.gov.au>, Helen Irving <Helen.Irving@health.qld.gov.au>, Sonya Stacey <Sonya.Stacey@health.qld.gov.au>, Michael Carroll <Michael.Carroll@health.qld.gov.au>, Stephen Greene <Stephen.Greene@health.qld.gov.au>
Subject: Re: Draft Minutes - Neurodevelopmental Disorders Steering Committee - 17th May 2017

Good Afternoon All,

Please see attached draft minutes from our meeting Wednesday.

Our next meeting will occur:

4pm, Wednesday 14th June 2017
Level 6 Boardroom
Centre for Children's Health Research
62 Graham Street, South Brisbane

If you have any agenda items, please forward them through to Emily.Milburn@health.qld.gov.au.

Kind regards

Emily

Emily Milburn

Project Support Officer (Neurodevelopmental Disorders)

Children's Health Queensland Hospital and Health Service
Level 6 – Centre for Children's Health Research

Lady Cilento Children's Hospital Precinct
62 Graham Street, South Brisbane QLD 4101
T: 07 3069 7457
E: Emily.Milburn@health.qld.gov.au
W: www.childrens.health.qld.gov.au

RTI Release

Minutes

Neurodevelopmental Disorders Steering Committee

Date:	17 th May 2017
Time:	4:00pm
Venue:	Level 6 Boardroom, Centre for Children's Health Research
Chair:	Dr Geoff Wallace
Secretary:	Emily Milburn
Attendees:	Dr Honey Heussler (HH); Prof Stephen Greene (SG); Michael Carroll (MC); Rochelle Greene (RG); Dr Sonya Stacey (SS); Dr Helen Irving (HI);
Apologies:	Dr Robyn Littlewood (RL); Dr Andrew Hallahan (AH); Melissa Fox (MF); Greg Perry (GP);

Item	Topics of discussion	Details of Discussion
1	Meeting opening	
1.1	Welcome and apologies	Geoff welcomed attendees and noted apologies – see above.
1.2	Confirmation of previous minutes	The minutes of the previous meeting held on Wednesday 12 th April 2017 were confirmed as true and correct.
2	Discussion	
2.1	CAS Update	<ul style="list-style-type: none"> Five of the approved participants have been prescribed. Out of 81 participants within eligibility criteria. 50% have gone to panel, 20 have come through successfully (found eligible).

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<p>2.2</p>	<p>Honey's Projects Update</p>	<p>Trial Status Update:</p> <p>s.73 - Irrelevant information (commercial) Trial monitoring visit occurred today – went well.</p> <ul style="list-style-type: none"> • One participant has been prescribed and is currently on Week 4 of the Trial. Going extremely well. Showing independence in school and social settings. • 2nd participant currently in screening. • Currently advertising for a HP3 Psych to perform assessments. <p>Ethics Amendment:</p> <ul style="list-style-type: none"> • Submitted to reduce age to 6 and to introduce an open label extension for at least 12 months and invite current participants to partake. • Received a query regarding safety data for use in children down to 2 years of age. Response to query submitted on Tuesday 16th. <p>Potential Collaborations:</p> <p>s.73 - Irrelevant information (commercial) are committed to rolling this study into other syndromes.</p> <ul style="list-style-type: none"> • Randomised controlled trial submitted to Marinus in the US for a trial in Ganaxolone – treatment of Angelman Syndrome. • GWP provided animal data using Sativex to HH. • HH to submit protocols to Ethics for observational trials <ul style="list-style-type: none"> ○ Potential for a study which would see a choice in CBD oil from GWP or gel from s.73 - Irrelevant information (commercial) • Potential for a n=1 comparison study. <ul style="list-style-type: none"> ○ GWP may object. ○ HH to discuss with s.73 - Irrelevant information (commercial) <p>Other updates:</p> <ul style="list-style-type: none"> • HH has acquired a quote for RedCap. <ul style="list-style-type: none"> ○ \$50,000 to integrate and \$18,000 every year after that. ○ HH and SG meeting with AI Sharman next week to discuss.
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