



Company Number: 7358100
Charity Number: 1139700

International Society for Gastrointestinal Hereditary Tumours

Agenda

A COUNCIL MEETING will be held
09:00 to 17:30 on Saturday 1st December 2018
The Board Room, The Wellington Hospital, London NW8 9LE

Susan Parry – Chairman

09:00	1.	Apologies	
	2.	Declaration of potential conflicts of interest	
09.05	3.	Minutes of last meeting i. Business arising	
09.15	4.	Administration matters i. Membership ii. Accounts iii. Honorary life members iv. Business meeting 2019 v. Council elections 2019 vi. Biennial meeting 2023	Jackie Hawkins Jackie Hawkins Sue Clark
09.45	5.	2019 Biennial Meeting in Auckland	Susan Parry
10.45		COFFEE	
11.00	6.	Secretary's Report	Finlay Macrae
11.15	7.	InSiGHT variant databases i. VIC Governance ii. Funding for InSiGHT curator iii. InSiGHT VIC as External Expert Panel for ClinGen iv. Formal relationship between Melbourne Health and InSiGHT (requested by MH) v. InSiGHT and IBM Watson (Artificial Intelligence) vi. InSiGHT databases MR research students and PhD (Michael Yates, Sheffield)	Finlay Macrae
12.15	8.	2021 Biennial Meeting	Tom Weber
12.45	9.	Endoscopy initiative	Andy Latchford
13.00	10.	LUNCH - InSiGHT Council PHOTO	
13.30	11.	Diploma in Cancer Genetic Counselling	James Church
14.15	12.	Website	Sue Clark
14.45	13.	InSiGHT goals and engagement i. Asia-Pacific group iii. CGA / EHTG including meeting Apps) iv. 'Finding Lynch Syndrome' – actions from previous meeting vii. Sponsorship/achievement award viii. Consumer involvement in future meetings	Finlay Macrae Sue Clark Tom Weber James Church
16.45	14.	Any other business	
	15.	Date and venue of next meeting March 2019 – Auckland	



Minutes of the Council Meeting
held on Saturday 1st December 2018
The Board Room, The Wellington Hospital, London NW8 9LE

Present:

Susan Parry (Chair), Gabriel Capella, Ian Frayling, Maurizio Genuardi, Andy Latchford, Patrick Lynch, Finlay Macrae, Allan Spigelman, Tom Weber, Sue Clark, Jackie Hawkins.

Action

1. Apologies

James Church, Nicoline Hoogerbrugge.

2. Declaration of potential conflicts of interest

Patrick Lynch, and Tom Weber declared that they are members of CGA in addition to InSiGHT. Gabriel Capella, Maurizio Genuardi, and Andy Latchford declared that they are members of EHTG. Sue Clark and Finlay Macrae declared that they are members of EHTG and CGA, and Ian Frayling that he is Treasurer Elect of EHTG and a member of CGA.

3. Minutes of last meeting

Minutes of the last meeting had been distributed in advance. Allan Spigelman proposed they be accepted as an accurate record, Maurizio Genuardi seconded, and Council agreed unanimously

i. Business arising

It was agreed that all matters would be covered by the meeting agenda.

4. Administration matters

i. Membership

Jackie Hawkins and Sue Clark reported that there had been some software difficulties with renewing expired membership, which had apparently been resolved by the provider. Because of this, and the fact that the majority of members transitioned to the electronic system when it was introduced two years ago and are therefore in the process of renewing currently, it is difficult to be precise about current membership, but this seems stable at about 225.

ii. Accounts

Jackie Hawkins reported the balance of the InSiGHT bank account to be approximately GBP 43,900.00. The accounts for the year ended 31 Aug 2018 are currently being prepared by the accountant. The completed accounts for the year ended 31 Aug 2017 have been submitted to the regulatory authorities and were presented.

It was agreed that the 'Just Giving' online donation facility should be retained despite its cost.

Sue Clark reminded Council that it had previously been agreed that it would be reasonable to spend GBP 5,000 per year for the next two years on the objectives of InSiGHT (eg bursaries, scholarships, educational materials or activities), and that this situation had not changed. A Vietnamese


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gastroenterologist has been supported to attend the meeting in Auckland, which will require some of this funding.

iii. Honorary life members

Kay Neale is coming to Auckland and Hans Vasen might attend. Juul Wijnen is not attending. Robin Phillips' plans are not clear; Sue Clark will clarify with him. Arrangements will be made to send certificates to those not attending.

Sue Clark
Jackie Hawkins

iv. Business meeting 2019

This will be held during the meeting in Auckland, at 16:45 on Friday 22 March. A draft agenda will be circulated to Council for approval.

Sue Clark
Jackie Hawkins

v. Council elections 2019

The call for nominations for election to Council is open. Voting will be conducted in the same way as the last election, both electronically and in person in Auckland. Sue Clark explained that, once again, the limit of 11 Council members, the possible need to retain a vacancy into which to co-opt the next Chair Elect (hosting 2023 meeting), but the desire to maximise the opportunities to join Council mean that the actual number of vacancies may not be clear until the election itself, or even the Council meeting at the end of 2019 when the venue of the 2023 meeting is confirmed.

Patrick Lynch proposed, and Andy Latchford seconded, that five vacancies be filled at the election. If and when it becomes clear that the incoming Chair Elect is actually already on Council, the candidate with the next highest number of votes will be invited to join Council. If the host of the 2023 meeting is not on Council they will be co-opted. Sue Clark will draft a document for approval by Council clarifying this; once approved it will be circulated to the membership with the election materials. Council agreed unanimously.

Sue Clark

vi. Biennial meeting 2023

Sue Clark reported that the call for expressions of interest in hosting the meeting in 2023 is open, closing on 1 January 2019. So far expressions of interest had been received from groups in Dublin and Nijmegen. All expressions of interest would be discussed at the brief Council meeting in Auckland to shortlist those to be invited to present more detailed proposals to Council in London in late 2019.

5. 2019 Biennial Meeting in Auckland

Susan Parry gave an update and presented the draft program. Of the 189 abstracts received and scored, about 40 can be presented orally, and most of the rest as posters. The format will consist of a named lecture to introduce a topic (with time for questions), followed by free papers on that topic. In order to accommodate as many presentations as possible Council agreed to shorten some of the invited talks, and that free papers would be allowed 5 minutes presentation plus 3 minutes discussion, with discussions of closely related papers being combined. Speakers will be instructed to limited superfluous introduction (given the specialist audience and preceding lecture). Abstract groupings, and the inclusion of some abstracts with borderline score, were discussed.



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She expressed her gratitude to invited speakers to have agreed to take part in the meeting without reimbursement of full expenses.

An 'app' is in production and there is already agreement that it will be available to CGA members a few weeks after the meeting.

Sue Clark requested that InSiGHT's support of a delegate from Vietnam be publicised.

6. Secretary's Report

Susan Parry

A written report had been circulated prior to the meeting and was presented by Finlay Macrae.

7. InSiGHT variants databases

i. VIC Governance

Finlay Macrae assured Council, on behalf of the VIC Governance Committee, that the Variants Databases and VICs continue to run in accordance with the SOPs previously tabled to Council.

The Terms of Reference of the VIC Governance Committee still requires some amendment (specifically appointment and duties of the chair) as suggested by Maurizio Genuardi, and an updated version will be submitted to Council once completed.

Maurizio Genuardi
Finlay Macrae

ii. Funding for InSiGHT curator

Finlay Macrae explained that the Royal Melbourne Hospital Foundation funding for the Variants Databases curator, John Paul Plazzer (who is employed by the Royal Melbourne Hospital), would cease at the end of 2018. Ongoing funding has been sought so far without success from a number of charitable organisations and from the Colon Family Register. Applications to the Cass Foundation and the Royal Melbourne Hospital Foundation are in progress.

Council discussed a number of options for obtaining ongoing funding, including charging commercial companies a fee for using data. This was considered to be difficult to police and administer. ClinGen, other academic institutions or commercial laboratories could be asked to contribute voluntarily. Patient groups such as Lynch Syndrome International could also be approached; this was thought not to be appropriate at this stage, although funding from patient groups could be seen to strengthen patient ownership of these patient derived data to some degree.

It was agreed that Council members would ask commercial laboratories for voluntary contributions which they could publicise, and that the views of Lynch Syndrome International on becoming financially involved would be sought.

Gabriel Capella suggested that InSiGHT make a contribution towards funding. Council agreed that GBP 5,000 could be committed at this point.

Finlay Macrae
Ian Frayling

iii. InSiGHT VIC as External Expert Panel for ClinGen

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Finlay Macrae explained that ClinGen has developed a genome-wide process to assign pathogenicity, which is somewhat different to the gene-specific process used by InSiGHT. A research project to compare the two approaches is underway.

iv. Formal relationship between Melbourne Health and InSiGHT

John Paul Plazzer has developed an app based on the InSiGHT criteria for pathogenicity assignment, aiming to make the process more straightforward. The requests for ongoing funding of his post have centred on funding a trial of this app. Ethical approval has been obtained. Governance approval has been delayed by Royal Melbourne Hospital, which requires a formal Research Collaboration agreement with InSiGHT.

Gabriel Capella suggest that two agreements were required, one generic to cover the Variants Databases and VICs, and another for the specific project proposed.

Council agreed that a legal opinion is required on the implications of the current draft agreement. Finlay Macrae agreed to amend and review the draft document with Melbourne Health with particular regard to financial obligations and data ownership (which rests with the data submitters).

Sue Clark agreed to get an initial legal opinion with regard to what is required to move forward.

Finlay Macrae

8. 2021 Biennial Meeting New York

Tom Weber explained that he had commenced discussion regarding involvement of CGA and the CFR in the meeting. Arrangements to obtain sponsorship and CME recognition are advanced. He considers 300 delegates the minimum to break even, but is aiming for 400 or more delegates plus their families. Accommodation for this number has been secured, along with a range of affordable options.

Sue Clark

Council supported suggestions that the meeting be extended from the traditional two and a half to three full days, that parallel sessions are avoided, and consideration be given to social event at the end. It is hoped that the CGA will be closely involved, perhaps with an emphasis on genetic counselling, and that there will be sessions to encourage collaborative research and global engagement

9. Endoscopy initiative

Susan Parry introduced the background to this initiative, which aims to outline standards for good quality endoscopy in inherited GI cancer in the form of an InSiGHT position statement. Andy Latchford presented a preliminary document outlining an approach to this, initially in upper GI endoscopy in FAP and colonoscopy in Lynch syndrome. In addition the aim is to signpost relevant national and international guidelines, and to attempt to ensure concordance between them as much as possible as they are developed.

Tom Weber

Council agreed that this is an important piece of work and that Andy Latchford and the working group (including Evelien Dekker and Carol Burke) continue this work, and give an update in Auckland.



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10. Diploma in Cancer Genetic Counselling

Andy Latchford
Susan Parry

James Church had communicated to Council in writing that Francisco Lopez in Santiago, Chile had not as yet provided an English translation of his course material, nor the requested information on previous graduates. Council agreed that the course could not be promoted or even advertised by InSiGHT without some scrutiny, and Gabriel Capella agreed to contact James Church and Francisco Lopez and offer to examine the course in Spanish, avoiding the need for translation, and feed back to Council.

Patrick Lynch agreed to obtain information about the course offered by the City of Hope Cancer Center in California. The aim in both these cases would simply be to assess whether courses are of sufficient quality and relevance to be signposted on the InSiGHT website.

James Church
Gabriel Capella

Finlay Macrae has a masters student from India undertaking a survey across Asia on genetic counselling services and training, which should inform future work in the region.

Patrick Lynch

11. Website

Sue Clark reminded Council members that they had agreed to take responsibility for individual subject areas to ensure that content remains up to date: Nicoline Hoogerbrugge - PHTS and HDGC; Finlay Macrae - Lynch syndrome/MMR genes and *POLE/POLD1*; Andy Latchford - JPS; Allan Spigelman - PJS; Maurizio Genuardi *MutYH/MAP*; Gabriel Capella - *APC/FAP*; James Church - surgery; Susan Parry - SPS and FPC. Encourage.

There was discussion of the current structure of the website and suggested modifications. It was agreed that a response to the NICE guidelines on pancreatic screening and reply to Council's letter raising concerns, should be posted on the website.

All Council members

12. InSiGHT goals and engagement

i. Asia-Pacific group

Sue Clark

Finlay Macrae reported that that about 30 people in the Asia-Pacific region, many of them genetic counsellors, are connected by email. A major challenge in integration across the region is the multiple languages in use.

Prof Zilfalil in Malaysia is still proposing a regional clinically orientated meeting on cancer genetics to coincide with Digestive Week in Kuala Lumpur in Sept 2020, but has not engaged further with InSiGHT.

A number of abstracts from authors in the region have been accepted for oral and poster presentation in Auckland, and an Asia-Pacific group meeting in Auckland is planned.

ii. CGA/EHTG

The EHTG has now been formally established, and several members of Council attended the inaugural meeting in Nice in September. Susan Parry reported that she had attended the CGA meeting, and was engaged in positive dialogue.



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Council expressed the importance of all three of these organisations flourishing, and that agreeing a Memorandum of Understanding with each of these would be mutually beneficial.

A draft MoU had been circulated in advance of the meeting. It was agreed that the leadership of CGA and EHTG should be approached informally in the first instance to discuss this.

Council agreed Susan Parry's proposal to organise a meeting between the leaders of these organisations and InSiGHT in Auckland.

Susan Parry
Ian Frayling
Finlay Macrae

iii. 'Finding Lynch syndrome'

Tom Weber updated Council on some of the multiple initiatives underway, and considerable progress that has been made.

Council acknowledged that James Church put in a huge amount of work to produce a draft paper, which is currently awaiting promised input from a number of contributors. Council agreed that members would assist with specific content and overall editing recommendations in as timely a manner as possible in response to James Church's requests, so that a final version could be completed as quickly as possible.

iv. Consumer involvement in future meetings

Susan Parry reported that she had received queries about patient involvement in the meeting in Auckland. There will be a public lecture the evening before the meeting, but as in previous years the meeting is for clinicians and scientists. Council expressed concern that in the past patient involvement in meetings had distracted from the main purpose and discussion, and was felt to be counter-productive. Tom Weber had involved patients directly in meetings he runs regularly, and did not find this detracted from them. Council agreed that the level of user involvement in the meeting in New York should be left up to him. Sue Clark suggested that more user-groups should be involved more in other aspects of the work of InSiGHT.

v. Sponsorship

It was agreed to put on agenda for next meeting.

13. Any other business

Gabriel Capella and Maurizio Genuardi explained that they are seeking EU funding and requested that they could name InSiGHT as a partnering institution in the application for international. They agreed to circulate background material, and Council agreed as long no member found the proposal unacceptable.

14. Date and venue of next meeting

Gabriel Capella

The next Council meeting will in Auckland in March 2019.

Council members were keen to identify other future dates to aid planning. It was agreed that there should be a meeting in London towards the end of



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2019 (perhaps to coincide with the proposed EHTG meeting in November), Summer 2020 and late 2020/ early 2021. Sue Clark agreed to find out the dates for the EHTG meeting, and circulate possible Council meeting dates.

Sue Clark

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