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**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/29/2020 8:16:13 PM  
**To:** Awwad, David (NIH/NIAID) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=0a5171ce4c4d4110abfe9aebfbdafbe7-dawwad]; Burrowes, Richard (NIH/NIAID) [C] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=708de6f2044a4656b303623d027a0fd-burrowesra]  
**CC:** Gilles, Sharon (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=339880516bcd4cddb7320d229399d09d-gillesm]  
**Subject:** FW: Slide set for NCI presentation this afternoon  
**Attachments:** CGC Summary for NIH International Clinical Research Subcommittee.pptx

Can we set this up for a 3:30 meeting?

---

**From:** Eiss, Robert (NIH/FIC) [E] (b)(6)  
**Sent:** Wednesday, January 29, 2020 3:14 PM  
**To:** Kline, Lydia (NIH/OD) [E] (b)(6); Smolskis, Mary (NIH/NIAID) [E] (b)(6); Tapley, Kate (NIH/OD) [E] (b)(6); Western, Karl (NIH/NIAID) [V] (b)(6); Millum, Joseph (NIH/CC/BEP) [E] (b)(6); Collier, Elaine (NIH/NCATS) [E] (b)(6); Engelgau, Michael (NIH/NHLBI) [V] (b)(6); Mensah, George (NIH/NHLBI) [E] (b)(6); Kutlesic, Vesna (NIH/NICHD) [E] (b)(6); Nightingale, Stuart (NIH/OD) [C] (b)(6); Gross, Thomas (NIH/NCI) [E] (b)(6); Berger, Adam (NIH/OD) [E] (b)(6); Rausch, Dianne (NIH/NIMH) [E] (b)(6); Higgs, Elizabeth (NIH/NIAID) [E] (b)(6); Auchincloss, Hugh (NIH/NIAID) [E] (b)(6); Handley, Gray (NIH/NIAID) [E] (b)(6); Harshman, Terri (NIH/NCI) [E] (b)(6); Sizemore, Christine (NIH/FIC) [E] (b)(6); Grady, Christine (NIH/CC/BEP) [E] (b)(6); Kilmarx, Peter (NIH/FIC) [E] (b)(6)  
**Cc:** Gilles, Sharon (NIH/NIAID) [E] (b)(6); Scharf, Sarah (NIH/FIC) [E] (b)(6)  
**Subject:** Slide set for NCI presentation this afternoon

Sharing NCI PPTs for those who may need . . .

---

**From:** Robert (NIH/FIC) [E]  
**Sent:** Wednesday, January 29, 2020 9:31 AM  
**To:** Kline, Lydia (NIH/OD) [E] (b)(6); Smolskis, Mary (NIH/NIAID) [E] (b)(6); Tapley, Kate (NIH/OD) [E] (b)(6); Western, Karl (NIH/NIAID) [V] (b)(6); Millum, Joseph (NIH/CC/BEP) [E] (b)(6); Collier, Elaine (NIH/NCATS) [E] (b)(6); Engelgau, Michael (NIH/NHLBI) [V] (b)(6); Mensah, George (NIH/NHLBI) [E] (b)(6); Kutlesic, Vesna (NIH/NICHD) [E] (b)(6); Nightingale, Stuart (NIH/OD) [C] (b)(6); Gross, Thomas (NIH/NCI) [E] (b)(6); Berger, Adam (NIH/OD) [E] (b)(6); Rausch, Dianne (NIH/NIMH) [E] (b)(6); Higgs, Elizabeth (NIH/NIAID) [E] (b)(6); Auchincloss, Hugh (NIH/NIAID) [E] (b)(6); Handley, Gray (NIH/NIAID) [E] (b)(6); Harshman, Terri (NIH/NCI) [E] (b)(6); Sizemore, Christine (NIH/FIC) [E] (b)(6); Grady, Christine (NIH/CC/BEP) [E] (b)(6); Kilmarx, Peter (NIH/FIC) [E] (b)(6); Officer, Jackie (NIH/FIC) [E] (b)(6); Nuriddin, Fajar (NIH/FIC) [C] (b)(6); Pringle, Beverly (NIH/NIMH) [E] (b)(6); Dickherber, Tony (NIH/NCI) [E] (b)(6)  
**Cc:** Gilles, Sharon (NIH/NIAID) [E] (b)(6); Sparks, Ariana (NIH/NIAID) [E] (b)(6); Scharf, Sarah (NIH/FIC) [E] (b)(6)  
**Subject:** RE: Confirmed: January 29 ICRS Meeting, 3:30PM- 5:00PM - Agenda

Dear all

Please note that we now will be meeting in **conference room 7A18**, which has become available, and where we typically convene the meeting. The call-in details remain the same.

Best regards,

---

**From:** Eiss, Robert (NIH/FIC) [E]

**Sent:** Tuesday, January 28, 2020 10:14 AM

**To:** Kline, Lydia (NIH/OD) [E] (b)(6); Smolskis, Mary (NIH/NIAID) [E] (b)(6); Tapley, Kate (NIH/OD) [E] (b)(6); Western, Karl (NIH/NIAID) [V] (b)(6); Millum, Joseph (NIH/CC/BEP) [E] (b)(6); Collier, Elaine (NIH/NCATS) [E] (b)(6); Engelgau, Michael (NIH/NHLBI) [V] (b)(6); Mensah, George (NIH/NHLBI) [E] (b)(6); Kutlesic, Vesna (NIH/NICHD) [E] (b)(6); Nightingale, Stuart (NIH/OD) [C] (b)(6); Gross, Thomas (NIH/NCI) [E] (b)(6); Berger, Adam (NIH/OD) [E] (b)(6); Rausch, Dianne (NIH/NIMH) [E] (b)(6); Higgs, Elizabeth (NIH/NIAID) [E] (b)(6); Auchincloss, Hugh (NIH/NIAID) [E] (b)(6); Handley, Gray (NIH/NIAID) [E] (b)(6); Harshman, Terri (NIH/NCI) [E] (b)(6); Sizemore, Christine (NIH/FIC) [E] (b)(6); Grady, Christine (NIH/CC/BEP) [E] (b)(6); Kilmarx, Peter (NIH/FIC) [E] (b)(6); Officer, Jackie (NIH/FIC) [E] (b)(6); Nuriddin, Fajar (NIH/FIC) [C] (b)(6); Pringle, Beverly (NIH/NIMH) [E] (b)(6); Dickherber, Tony (NIH/NCI) [E] (b)(6);  
**Cc:** Gilles, Sharon (NIH/NIAID) [E] (b)(6); Sparks, Ariana (NIH/NIAID) [E] (b)(6); Scharf, Sarah (NIH/FIC) [E] (b)(6);

**Subject:** Confirmed: January 29 ICRS Meeting, 3:30PM- 5:00PM - Agenda

Dear colleagues,

This is to reconfirm the next meeting of the International Clinical Research Subcommittee, to convene on **Wednesday, January 29, from 3:30 PM -5:00 PM**. The conference room location is Building 31, Room 7A21

Attached is an agenda. We welcome any suggested additional items/updates.

For those unable to join in person, following are call in -details

Join Skype Meeting  
Trouble Joining? Try Skype Web App  
Join by phone

(b)(6) (NIAID) (NIAID)

English (United States)  
English (United States)

Find a local number

Conference ID: (b)(6)  
Forgot your dial-in PIN? | Help

Please advise if you have any questions

Best regards,

-----Original Appointment-----

**From:** Eiss, Robert (NIH/FIC) [E]

**Sent:** Wednesday, January 22, 2020 2:56 PM

**To:** Kline, Lydia (NIH/OD) [E]; Smolskis, Mary (NIH/NIAID) [E]; Tapley, Kate (NIH/OD) [E]; Western, Karl (NIH/NIAID) [V];

Millum, Joseph (NIH/CC/BEP) [E]; Collier, Elaine (NIH/NCATS) [E]; Engelgau, Michael (NIH/NHLBI) [V]; Mensah, George (NIH/NHLBI) [E]; Kutlesic, Vesna (NIH/NICHD) [E]; Nightingale, Stuart (NIH/OD) [C]; Gross, Thomas (NIH/NCI) [E]; Berger, Adam (NIH/OD) [E]; Rausch, Dianne (NIH/NIMH) [E]; Higgs, Elizabeth (NIH/NIAID) [E]; Auchincloss, Hugh (NIH/NIAID) [E]; Handley, Gray (NIH/NIAID) [E]; Harshman, Terri (NIH/NCI) [E]; Flores Rivas, Silvia (NIH/NIAID) [E]; Sizemore, Christine (NIH/FIC) [E]; Grady, Christine (NIH/CC/BEP) [E]; Kilmarx, Peter (NIH/FIC) [E]; Officer, Jackie (NIH/FIC) [E]; Nuriddin, Fajar (NIH/FIC) [C]; Pringle, Beverly (NIH/NIMH) [E]

**Subject:** January ICRS Meeting

**When:** Wednesday, January 29, 2020 3:30 PM-5:00 PM (UTC-05:00) Eastern Time (US & Canada).

**Where:** Building 31, Room TBD

Dear colleagues,

We are rescheduling tomorrow's ICRS meeting to next week, due to conflicting commitments. The meeting will now take place on **Wednesday, January 29, from 3:30 PM-5:00 PM**. I will confirm the conference room location in Building 31. Could you kindly confirm your availability so that we can ensure this date is viable for the group? Thanks for your flexibility

Following are planned agenda topics, and welcome additional ideas:

- *Wuhan coronavirus – plans for a response*
- *GDPR update*
- *Relevant items from World Economic Forum (Dr. Collins participating)*
- *HIROs annual meeting in March*
- *Update on the NIH Common Fund's Harnessing Data Science for Health Discovery and Innovation in Africa program*
- *NCI- Cancer Research UK Grand Challenges - a novel funding model (tentative)*
- *Update on ClinRegs (tentative)*

I am very pleased to welcome Dr. Dianne Rausch to the group. Dianne is replacing Beverly Pringle, (b)(6) I anticipate many of you know Dianne, who serves as Director of NIMH's Division of AIDS Research.

Best,

# Cancer Grand Challenges

A New NCI Program in Collaboration with  
Cancer Research UK (CRUK)

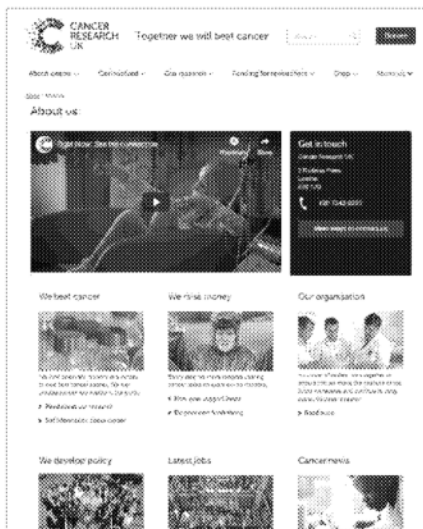
*Tony Dickherber*  
*Center for Strategic Scientific Initiatives*  
*Jan 28, 2020*

 NATIONAL CANCER INSTITUTE



## Outline

1. *Overview of the Initiative*
2. *Collaboration Development*
3. *Where are we now?*
4. *Longer term considerations*



<https://www.cancerresearchuk.org/about-us>

## Cancer Research UK (CRUK)

- World's largest independent cancer research charity
- £413 million (\$531 million), financial year 2017-18
- Mission to promote public health by research into the causes, diagnosis, prevention and treatment of cancer
- Research funding through various mechanisms:
  - Investigator-initiated grants
  - Training fellowships
  - Research infrastructure (institutes and centers)
- 150+ research partnerships worldwide

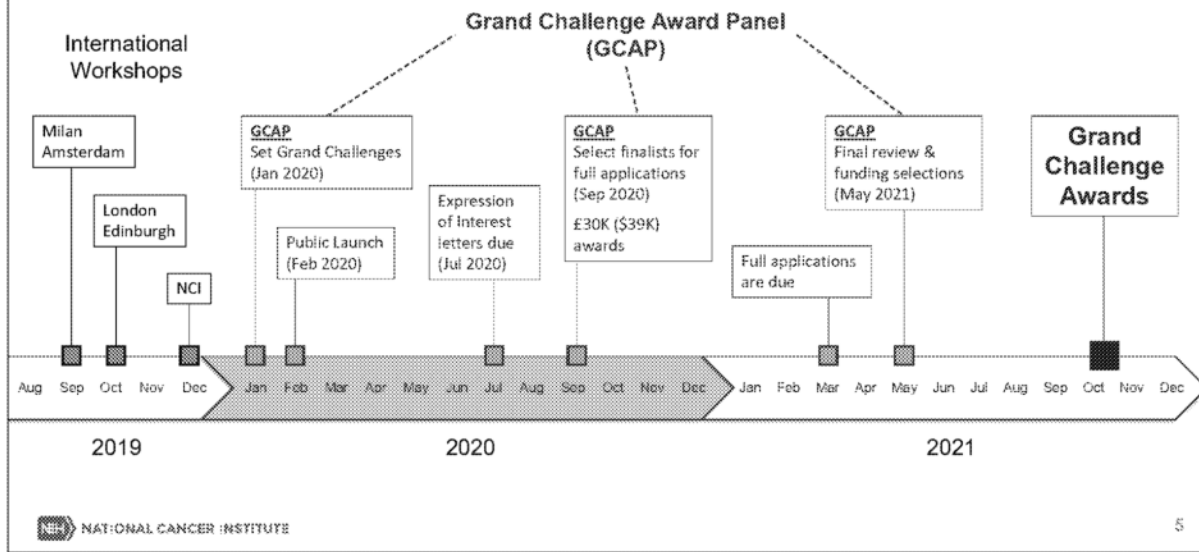
*"...partnerships enable mutually beneficial research collaborations with like-minded organisations... accelerating progress in the fight against cancer."*

## Major Goals

- Identify specific barriers that, if removed, would be transformative and unlock the potential for patient benefit
- Fund a portfolio of novel and innovative research to address the challenges
- Encourage multi-disciplinary approaches and attract new thinking to cancer research
- Train future leaders in cancer research
- Facilitate global collaboration among researchers

Funded Awards (2017-2019)	
<b>Investigators</b>	International teams; 8-15 investigators; 5-8 institutions; 3+ countries (on average)
<b>Funding Scale</b>	~ £20 million (\$26 million)
<b>Number of Awards</b>	3-4 per funding round (biennial)
<b>Award Period</b>	Generally 5 years (flexible)

# Grand Challenge Process



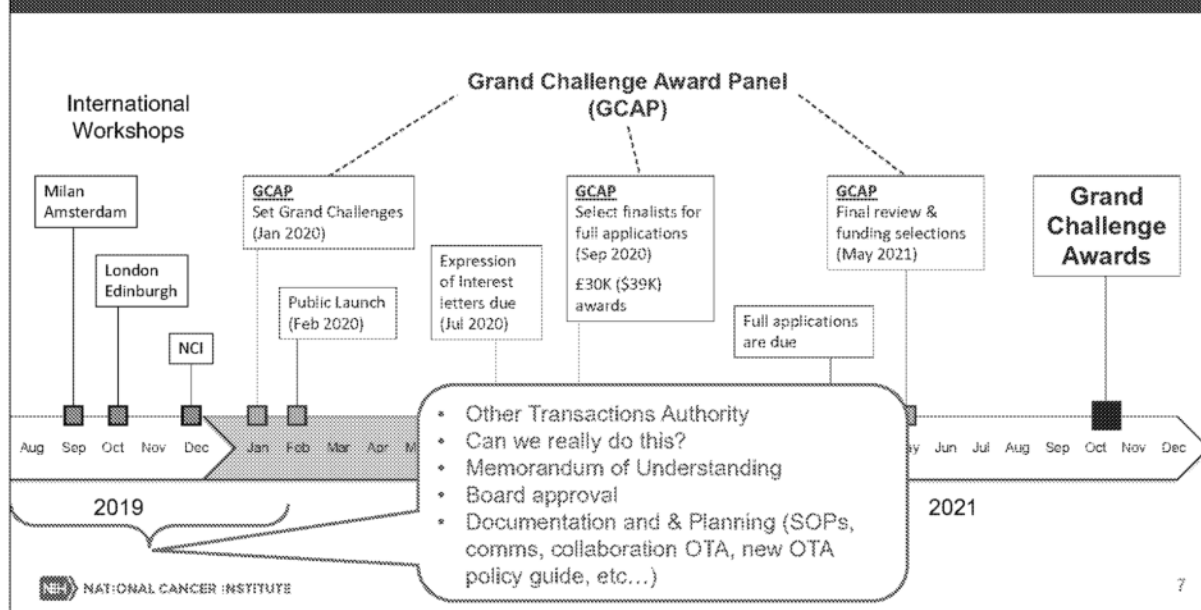




## Outline

1. *Overview of the Initiative*
2. *Collaboration Development*
3. *Where are we now?*
4. *Longer term considerations*

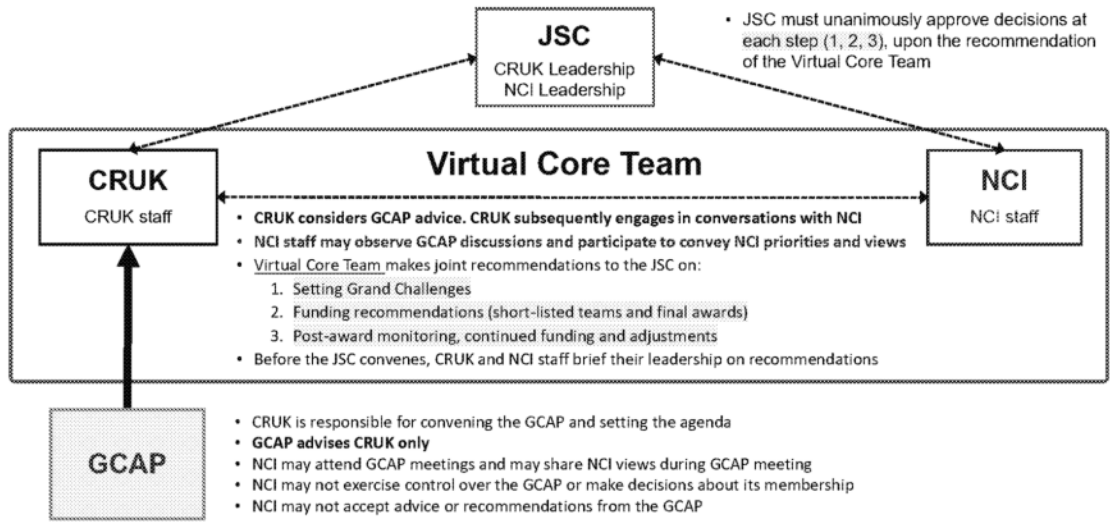
# Grand Challenge Process



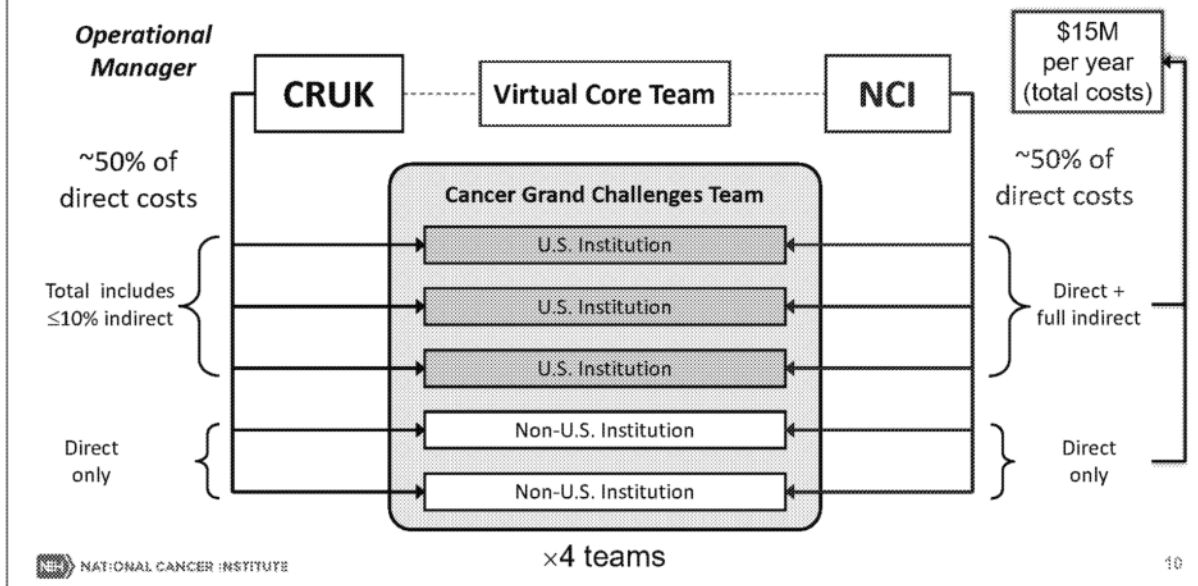
## Partnership Agreement with CRUK

- NCI will partner with CRUK to co-fund approximately four Grand Challenge awards per biennial funding round (×3 rounds)
- NCI funding will be awarded using the Other Transactions Authority (OTA) mechanism
- Funded teams will sign a master Funding and Collaboration Agreement (FCA) co-developed by CRUK and NCI
- All decisions regarding the Partnership will be approved by a Joint Steering Committee comprising CRUK and NCI leadership

# Governance Model



# Funding and Operations

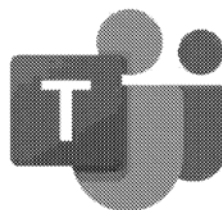
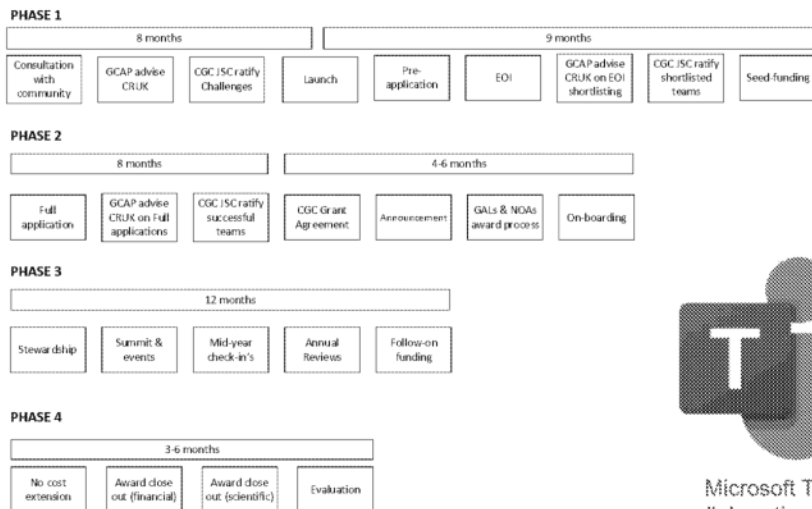




## Outline

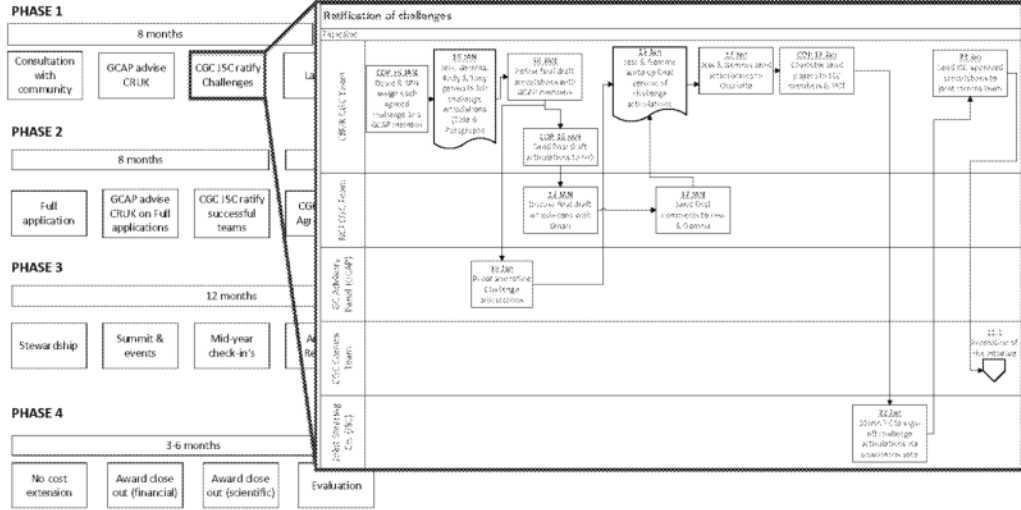
1. *Overview of the Initiative*
2. *Collaboration Development*
3. ***Where are we now?***
4. *Longer term considerations*

# Operational Planning Nitty Gritty



Microsoft Teams is the collaboration tool of choice

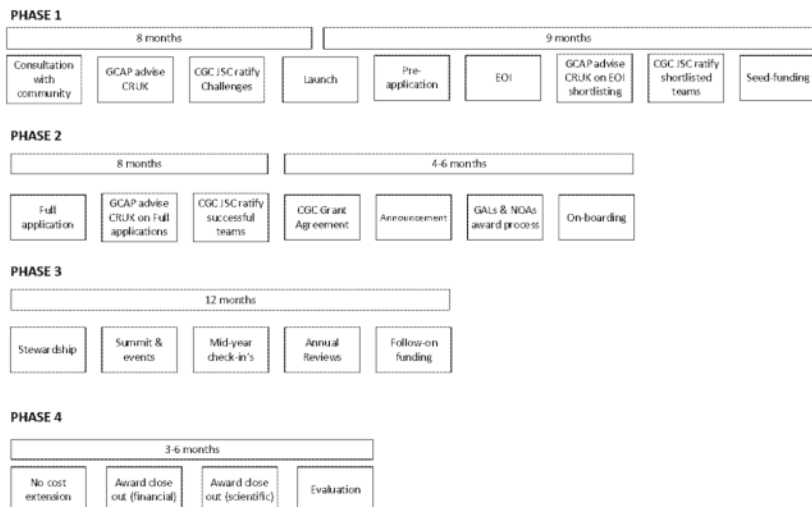
# Operational Planning Nitty Gritty







# Operational Planning Nitty Gritty



## Current Hurdles

- Finalizing an OTA Policy Guide
- Communication and collaboration across 5 time zones (requiring a fair amount of travel)
- Building all the necessary SOPs
- CRUK must apply for OTA funding through a limited competition FOA
  - Identifying costs that can be shared
- Continuously maintaining trust



## Outline

1. *Overview of the Initiative*
2. *Collaboration Development*
3. *Where are we now?*
4. *Longer term considerations*

## Looking Ahead

- Need to finalize MOU!
- Successful public launch (February)
- Set up a Collaboration OTA to allow cost sharing
- Complete our operational planning
- Start thinking about evaluation planning



**NATIONAL  
CANCER  
INSTITUTE**

[www.cancer.gov](http://www.cancer.gov)

[www.cancer.gov/espanol](http://www.cancer.gov/espanol)

**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/22/2020 5:15:12 PM  
**To:** Old, Susan (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=d0a7b4acc587484fb51bbe8bd6659512-oldse]; Fenton, Matthew (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=82033fcff24546799c3310788d74d9da-fentonm]; Marston, Hilary (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=ab30660917b942ffba9ae95d631116f3-marstonhd]  
**CC:** Gilles, Sharon (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=339880516bcd4cddb7320d229399d09d-gillesm]; Harper, Jill (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=0bfd6dfb8e48482fb49a5f72abfcbac8-jharper]; Eisinger, Robert (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=0bad2a8c45514ee48985880de66674ad-eisinger]; Lerner, Andrea (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=53254f4fb04e4bcbabe37940b4b41887-fennellyam]; Wurster, Andrea (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=1d08c246ea5d4b95afb03b36b8f38136-wurster]; Linde, Emily (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=b2fd661421cd499b8f7fad6a196f6b02-lindee]; Connors, Victoria (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=f2986daee161438bb291739c997b5d9d-connorsv]  
**Subject:** RE: Rapid FOA

(b)(5) Please proceed as we discussed.

Hugh

Hugh Auchincloss, M.D.  
Deputy Director, NIAID  
National Institutes of Health  
Bldg. 31 (7A/03), 31 Center Drive, MSC 2520  
Bethesda, MD 20892  
Phone: (b)(5)

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**From:** Old, Susan (NIH/NIAID) [E] (b)(6)  
**Sent:** Wednesday, January 22, 2020 10:21 AM  
**To:** Fenton, Matthew (NIH/NIAID) [E] (b)(6); Marston, Hilary (NIH/NIAID) [E] (b)(6)  
**CC:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6); Gilles, Sharon (NIH/NIAID) [E] (b)(6); Harper, Jill (NIH/NIAID) [E] (b)(6); Eisinger, Robert (NIH/NIAID) [E] (b)(6); Lerner, Andrea (NIH/NIAID) [E] (b)(6); Wurster, Andrea (NIH/NIAID) [E] (b)(6)

(b)(6) Linde, Emily (NIH/NIAID) [E] (b)(6); Connors, Victoria (NIH/NIAID) [E]

**Subject:** RE: Rapid FOA

Hilary,

We are setting up the internal SOP with a working group with Program and DEA.

Our process begins with Hugh's approval (right now by email). We will want to get OPERA's concurrence prior to submitting so we can add that to the FOA system.

So I would suggest

1. Hugh send an approval email to you
2. You work with Andrea to initiate the FOA so it has all the right parts
3. Andrea will send to OPERA once she has the aims of the FOA

We should be able to do this as quickly as you need.

Susan

---

**From:** Fenton, Matthew (NIH/NIAID) [E] (b)(6)  
**Sent:** Wednesday, January 22, 2020 9:38 AM  
**To:** Marston, Hilary (NIH/NIAID) [E] (b)(6)  
**Cc:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6); Gilles, Sharon (NIH/NIAID) [E]  
(b)(6) Harper, Jill (NIH/NIAID) [E] (b)(6) Eisinger, Robert (NIH/NIAID) [E]  
>; Lerner, Andrea (NIH/NIAID) [E] (b)(6) Wurster, Andrea (NIH/NIAID) [E]  
>; Old, Susan (NIH/NIAID) [E] (b)(6)  
**Subject:** Re: Rapid FOA

Here's the parent FOA, and it includes links to recent NOSIs from ICs who used this mechanism:

<https://grants.nih.gov/grants/guide/pa-files/PA-18-935.html>

Matthew

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**From:** Fenton, Matthew (NIH/NIAID) [E] (b)(6)  
**Sent:** Wednesday, January 22, 2020 8:30:47 AM  
**To:** Marston, Hilary (NIH/NIAID) [E] (b)(6)  
**Cc:** Auchincloss, Hugh (NIH/NIAID) [E] (b)(6); Gilles, Sharon (NIH/NIAID) [E]  
(b)(6) Harper, Jill (NIH/NIAID) [E] (b)(6) Eisinger, Robert (NIH/NIAID) [E]  
>; Lerner, Andrea (NIH/NIAID) [E] (b)(6) Wurster, Andrea (NIH/NIAID) [E]  
>; Old, Susan (NIH/NIAID) [E] (b)(6)  
**Subject:** Re: Rapid FOA

Hilary - I'm out of the country this week, but essentially the process begins with requesting permission from OER to issue a urgent award NOSI (remember, these are supplements, but allow work outside of the scope of the parent grant), then we draft the NOSI and submit it for publication in the NIH Guide. Supplement requests will be reviewed by program staff, so DMID will need to assemble a "review panel" of Program Officers. Once approved, GMP will add the supplement funds to the parent awards.



Susan and Andrea Wurster (Ken Santora's successor) can provide more detail. I don't recall if these is a form that Tony needs to fill out to request permission from OER, but perhaps just an email with a description of the need and justification will do.

Matthew

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**From:** Marston, Hilary (NIH/NIAID) [E] (b)(6)  
**Sent:** Wednesday, January 22, 2020 8:25 AM  
**To:** Fenton, Matthew (NIH/NIAID) [E]  
**Cc:** Auchincloss, Hugh (NIH/NIAID) [E]; Gilles, Sharon (NIH/NIAID) [E]; Harper, Jill (NIH/NIAID) [E]; Eisinger, Robert (NIH/NIAID) [E]; Lerner, Andrea (NIH/NIAID) [E]  
**Subject:** Rapid FOA

Matthew, (b)(5) can you remind us of the process?

Many thanks.

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**From:** Auchincloss, Hugh (NIH/NIAID) [E] [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=9304C753BB9E422C977DDDAB54DA924B-AUCHINCLOSS]  
**Sent:** 1/22/2020 5:49:06 PM  
**To:** Kastner, Daniel (NIH/NHGRI) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=eff65151186e49c89eb91a461c33ba0d-kastnerd]  
**CC:** McGowan, John J. (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=fd4549a1a37c41c78410c7c29e3d3c00-jmcgowan]; Harper, Jill (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=0bfd6dfb8e48482fb49a5f72abfcbac8-jharper]; Johnson, Martin S. (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=2f99dc80ec43431a8724a4f30ed42e5c-msjohnson]; Crum, Wayne (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=8557255af9474b59b199aeac9c407698-wcrum]; Gilles, Sharon (NIH/NIAID) [E] [/o=ExchangeLabs/ou=Exchange Administrative Group (FYDIBOHF23SPDLT)/cn=Recipients/cn=339880516bcd4cddb7320d229399d09d-gillesm]  
**Subject:** FW: Tin-cupping for the 2020 International Summit in Genetics and Genomics  
**Attachments:** ISHGG 2019\_Agenda[1].pdf; ISHGG 2019\_DIR report\_Final[1][1].pdf; Annual Report 2018 10072019\_Final[1].pdf

Dan, NIAID would be happy to contribute (b)(5) to this Summit.

Hugh

Hugh Auchincloss, M.D.  
Deputy Director, NIAID  
National Institutes of Health  
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Bethesda, MD 20892  
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**From:** Kastner, Daniel (NIH/NHGRI) [E] (b)(6)  
**Sent:** Tuesday, January 21, 2020 9:59 PM  
**To:** Fauci, Anthony (NIH/NIAID) [E] (b)(6)  
**Cc:** Kaur, Manjit (NIH/NHGRI) [E] (b)(6); Solomon, Ben (NIH/NHGRI) [E] (b)(6)  
**Subject:** Tin-cupping for the 2020 International Summit in Genetics and Genomics  
**Importance:** High

Hi Tony,

I hope all is well with you. I'm writing in my capacity as Scientific Director of the NHGRI to thank you for your generous support of the 2019 International Summit in Genetics and Genomics. Last year we hosted 34 participants from low to middle-income countries (LMICs, as defined by the World Bank in 2019) for this month-long program. To date, we have trained 105 healthcare professionals from 43 different countries. Please see attached details, including the most recent report and last year's agenda.

AUCH0000005646

In short, the purpose of this trans-NIH initiative is to advance the field of Genetics and Genomics in resource-poor countries. The Summit also helps extend the reach of the NIH to the global community.

To continue the program in 2020, I'm hoping that you will extend your previous support of \$20,000/year, and would appreciate if you would let us know if this is something that you are able and willing to do, so that we can work on documentation and logistics. In 2020 we hope to host 40 trainees. Each selected participant costs \$20,000 to cover expenses such as travel, housing, and meals. We appreciate any amount we receive from you; sponsoring at least one full participant would be ideal.

Please let us know if you have any questions or if we can help in any way. I am cc'ing Manjit Kaur, who administers the program, and Ben Solomon, the new Clinical Director of NHGRI.

With my very best wishes,

Dan

**National Human Genome Research Institute  
National Institutes of Health  
August 29 – September 27, 2019**

**Agenda**

**Bldg 35A, Room 610**

	<b>Topic</b>	<b>Speaker</b>
<b>Aug. 29 (Thur)</b>		
8:00 – 8:30 am	Registration	Please bring Passports and visas
8:30 – 8:45 am	SURVEY and PHOTO	
8:45 – 9:00 am	Welcome	Dr. Eric Green Director, NHGRI  Dr. Max Muenke Chief, Medical Genetics Branch, NHGRI
9:00– 10:00 am	The Human Genomics Landscape, Circa 2019	Dr. Eric Green Director, NHGRI
10:00 – 10:30 am	BREAK	
10:30 – 11:30 pm	Overview: Approach to Clinically- Oriented Genetics and Genomics	Dr. Ben Solomon Managing Director, GeneDx
11:30 am – 12:30 pm	Common Conditions and Disease Patterns	Dr. Ben Solomon Managing Director, GeneDx
12:30 – 1:30 pm	LUNCH	
1:30 – 2:30 pm	Patterns of Inheritance and Key Terminology	Dr. Ben Solomon Managing Director, GeneDx
2:30 – 2:45 pm	BREAK	
3:00 – 4:50 pm	CLINICAL CENTER TOUR*:  Metabolic Unit Group A: 3:00-3:30 Group B: 3:40-4:10  Pediatric Unit (1NW) Group B: 3:00-3:30 Group A: 3:40-4:10  Clinical Center (4:20-4:50)	Drs. Kong Chen and Stephanie Chung Clinical Investigators, NIDDK and Co-directors, Metabolic Clinical Research Unit, NIH Clinical Center  Dr. Cynthia Tiff Deputy Clinical Director, NHGRI  Ms. Laura M. Lee, MS, RN Director, Office of Patient Safety and Clinical Quality NIH Clinical Center
4:50 – 5:00 pm	Survey	

\*Break into 2 groups

**Bldg. 45 (Natcher Conference Center), Room F1/F2**

	<b>Topic</b>	<b>Speaker</b>
<b>Aug. 30 (Fri)</b>		
7:45 – 8:00 am	SURVEY	
8:00 – 9:00 am	The Role of Race, Ethnicity and Socioeconomic Status in Clinical Genetics Research	Dr. Eliseo Perez-Stable Director, NIMHD
9:00 – 10:00 am	NIH Undiagnosed Disease Program	Dr. William Gahl Director, Undiagnosed Disease Program NHGRI
10:00 – 10:30 am	BREAK	
10:30 – 11:30 am	Skeletal Dysplasias	Dr. Julie Hoover-Fong Director, Greenberg Center for Skeletal Dysplasias Associate Professor of Genetic Medicine and Pediatrics, Johns Hopkins University
11:30 – 1:00 pm	LUNCH	
1:00 – 2:00 pm	Gene Therapy for Sickle Cell Anemia	Dr. Matt Hsieh Staff Clinician, Cellular and Molecular Therapeutics Branch, NHLBI
2:00 – 3:00 pm	Auto-Inflammatory Disorders	Dr. Dan Kastner, Scientific Director, NHGRI
3:00 – 3:30 pm	BREAK	
3.30- 4:30 pm	Genetics of Complex Traits	Dr. Lawrence Brody Director, Division of Genomics and Society, NHGRI
4:30 – 5:30 pm	Genetics of Lipid Disorders	Dr. Robert Shamburek Clinician/Scientist, Lipid Section Cardiovascular Branch, NHLBI
5:30- 5.45 pm	SURVEY	

**Bldg 35A Room, 610**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 3 (Tue)</b>		
7:45 – 8:00 am	SURVEY	
8:00 – 9:00 am	A Clinical Approach to a Patient with a Suspected Genetic Disorder	Dr. Adebowale Adeyemo Deputy Director, Center for Research in Genomic and Global Health, Associate Investigator, National Human Genome Research Institute, NHGRI
9:00 – 9:30 am	BREAK	
9:30 – 11:30 am	Cytogenetics	Dr. Jeanne Meck Director, Prenatal Diagnosis & Cytogenomics, GeneDx
11:30 - 1.00 pm	LUNCH	
1:00 – 2:00 pm	Clinical Aspects of Cytogenetic Disorders	Dr. Clesson Turner Clinical Geneticist, Walter Reed National Military Medical Center
2:00 – 3:00 pm	Sickle Cell Disease, The Global Health Burden	Dr. Vence Bonham Senior Advisor to the NHGRI Director on Genomics and Health Disparities, NHGRI
3:00 – 3:30 pm	BREAK	
3.30- 4:30 pm	Microbiome	Dr. Hernan Lorenzi Assistant Professor Infectious Disease Group J. Craig Venter Institute
4:30 – 5:30 pm	Neurogenetics	Dr. Sonja Scholz Investigator, Neurodegenerative Diseases Research Unit, NINDS
5:30- 5.45 pm	SURVEY	

**Meet at The Gateway Visitor's Center, NIH**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 4 (Wed)</b>		
8.00 – 8.15 am	Survey on the bus	
8:30 am – 5:00 pm	<p>Field Trip-            NIH Intramural Sequencing Center            (NISC) 8.30-10.30 am            5625 Fishers Lane            Rockville, MD 20852</p> <p>National Center for Advancing            Translation Sciences (NCATS)            11.00-12.40 pm            9800 Medical Center Dr., Rockville,            MD 20850</p> <p>GeneDX 1.00- 4.30 pm            207 Perry Pkwy, Gaithersburg, MD            20877</p> <p>Survey on the bus</p>	

**Bldg. 45 (Natcher Conference Center), Room F1/F2**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 5<sup>th</sup> (Thur)</b>		
7:45 – 8.00 am	SURVEY	
8.00 – 10.00 am	Grant Writing- Part 1: The structure of a grant proposal (General and K43)	Dr. Beth Fischer, Assistant Professor of School of Education, University of Pittsburgh  Dr. Michael Zigmond, Professor Emeritus, University of Pittsburgh
10:00 – 10:30 am	BREAK	
10:30 – 12:30 pm	Grant Writing- Part 1 continued: The process of preparing and submitting a proposal	
12:30 – 1:30 pm	LUNCH (can include group discussions)	
1:30 – 3:00 pm	Group discussion: Candidates present their specific aims to their group and get feedback	
3:00 – 3:30 pm	BREAK	
3:30 – 5:30 pm	Grant Writing- Part 2 (focus on specific aims): Insights from group discussions, review of basic principles of a fundable set of specific aims, final Q & A	
5:30 – 5:45 pm	SURVEY	

**Manjit has group list**



**Bldg. 45 (Natcher Conference Center), Room F1/F2**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 6<sup>th</sup> (Fri)</b>		
7:45 – 8:00 am	SURVEY	
8:00 – 9:15 am	Overview of Fogarty Extramural Programs	Dr. Laura Povlich Fogarty International Center/NIH
	The Emerging Global Leader Award (K43): A Career Development Award for LMIC Investigators	Dr. Christine Jessup, Fogarty International Center/NIH
9:15 – 9:45 am	Research and Development at USAID: Opportunities for Engagement	Dr. Megan Miller Research Program Officer Center for Development Research, USAID
9:45 – 10:15 am	An Overview of Clinical Gene Therapy	Dr. Kenneth Cornetta Professor of Clinical Medical & Molecular Genetics, Indiana University School of Medicine
10.15 - 10.45 am	BREAK	
10.45 - 11.45 am	CRISPR/Cas9 Technology	Dr. Shawn Burgess Senior Investigator, Translational and Functional Genomics Branch, NHGRI
11.45 - 1.00 pm	LUNCH	
1:00 – 2:00 pm	Genetics of Alzheimer's Disease and Related Dementias	Dr. Marilyn Miller Program Director, Genetics of Alzheimer's Disease, NIA
2:00 – 3:00 pm	Genetics of Mood and Anxiety Disorders	Dr. Francis McMahon, Chief Human Genetics Branch, NIMH
3:00 – 3:30 pm	BREAK	
3:30 – 4:30 pm	Genetic and Environmental Contributions to Psychiatric and Substance Use Disorders	Dr. Brion Maher Professor of Mental Health Johns Hopkins Bloomberg School of Public Health
4:30 – 5:30 pm	Epigenetics in Human Health and Disease	Dr. Laura Elnitski Senior Investigator, Translational and Functional Genomics Branch, NHGRI
5:30 – 5:45 pm	SURVEY	

**Bldg. 45 (Natcher Conference Center), Room C1/C2**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 9<sup>th</sup> (Mon)</b>		
7:45 – 8:00 am	SURVEY	
8:00 – 9:00 am	Genetic Counseling	Mr. Don Hadley Certified Genetic Counselor Deputy Director, Medical Genetics & Genomic Medicine Residency, NHGRI
9:00 – 10:00 am	Variant Nomenclature	Dr. Christopher Lau Clinical Molecular Geneticist, Associate Laboratory Director, Clinical Diagnostics, Ambry Genetics
10:00 – 10:30 am	BREAK	
10:30 – 11:30 am	Variant Interpretation	Dr. Christopher Lau Clinical Molecular Geneticist, Associate Laboratory Director, Clinical Diagnostics, Ambry Genetics
11:30am-1:00 pm	LUNCH	
1:00 – 2:00 pm	Traumatic Brain Injury	Dr. Jessica Gill, Senior Investigator Acting Scientific Director, NINR
2:00 – 3:00 pm	Growing Success Stories of Genomics in African Ancestry Populations: H3 Africa and Beyond	Dr. Charles Rotimi Director, Center for Research on Genomics and Global Health, Chief & Senior Investigator, Metabolic, Cardiovascular and Inflammatory Disease Genomics Branch, NHGRI
3:00 – 3:30 pm	BREAK	
3:30 – 4:15 pm	Genetic Syndromes in Diverse Populations	Dr. Paul Kruszka, MD, MPH Associate Research Physician, NHGRI
4:15 – 5:30 pm	Patient Panel	Moderator Mr. Don Hadley Certified Genetic Counselor Deputy Director, Medical Genetics & Genomic Medicine Residency, NHGRI
5:30- 5.45 pm	SURVEY	

**Meet at The Gateway Visitor's Center, NIH**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 10<sup>th</sup> (Tue)</b>		
7:00 – 7:15 am	Survey on the bus	
8:30 – 5:00 pm	Field Trip- Johns Hopkins University 8:30 am-12:00 pm 733 N Broadway, Baltimore, MD 21205  Lunch at JHU 12:00-12:30 pm  Kennedy Krieger Institute 12.30 pm- 2.15 pm  Maryland Newborn Screening Laboratory 2:30 pm- 4:30 pm  Survey on the bus	

**Bldg. 45 (Natcher Conference Center), Room A/B  
And  
Bldg 31, Room B1E12**

	Topic		Speaker
<b>Sept. 11<sup>th</sup> (Wed)</b>			
7:45 – 8:00 am	SURVEY		
	Group A*	Group B*	
8:00 – 9:30 am	Molecular Genetics (Bldg 45 Room A/B)	Bioinformatics workshop (8 am-12 pm) – Bldg 31 room B1E12; Dr.	Dr. Suzanne Hart Deputy Director, Medical Genetics & Genomic Medicine Training Program, NHGRI
9:30 – 10:30 am	Genetics of Genitourinary Disorders	Tyra Wolfsberg, Associate Director Bioinformatics and Scientific	Dr. Melissa Merideth Attending Ob/Gyn and Geneticist Director, Medical Biochemical and Clinical Biochemical Training Programs
10:30 – 11:00 am	BREAK	Programming	
11:00 – 12:00 pm	How to Write a Scientific Paper	Core, NHGRI	Dr. Max Muenke Chief, Medical Genetics Branch, NHGRI
12:00 – 1:00 pm	LUNCH		
	Group A*	Group B*	
1:00 – 2:30 pm	Bioinformatics workshop (1-5 pm) - Bldg 31 room B1E12; Dr. Tyra	Molecular Genetics (Bldg 45 Room A/B)	Dr. Suzanne Hart Deputy Director, Medical Genetics & Genomic Medicine Training Program, NHGRI
2:30 – 3:30 pm	Wolfsberg, Associate Director Bioinformatics and Scientific	Genetics of Genitourinary Disorders	Dr. Melissa Merideth Attending Ob/Gyn and Geneticist Director, Medical Biochemical and Clinical Biochemical Training Programs
3.30 – 4:00pm	Programming	BREAK	
4:00 – 5:00 pm	Core, NHGRI	How to Write a Scientific Paper	Dr. Max Muenke Chief, Medical Genetics Branch, NHGRI
5:00 – 5:15 pm	SURVEY		

**\*Manjit has group list**

**Bldg 35A, Room 640**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 12<sup>th</sup> (Thur)</b>		
7:45 – 8:00 am	SURVEY	
8:00 – 9:00 am	Neurocutaneous Syndromes	Dr. Dusica Babovic-Vuksanovic Chair, Department of Clinical Genomics, Mayo Clinic
9:00 – 10:00 am	Clinical Trials in the Study of Rare Diseases	Dr. Cynthia Tifft Deputy Clinical Director, NHGRI
10:00 – 10:30 am	BREAK	
10:30 – 11:30 am	Inherited Pulmonary Disorders	Dr. Bernadette Gochuico Senior Research Physician Attending Pulmonologist Medical Genetics Branch, NHGRI
11:30 – 12:45pm	LUNCH	
1:00 – 2:00 pm	Genetics of Arrhythmia and Cardiomyopathy	Dr. Elizabeth Sherwin Pediatric Electrophysiologist, CNHS
2:00 – 3:00 pm	Genetics of Cardiac Structural Defects	Dr. Laura Olivieri Pediatric Cardiologist, CNHS
3:00 – 3:30 pm	BREAK	
3:30 – 4:30 pm	What Makes Research Ethical?	Mr. Ben Berkman Faculty, NIH Department of Bioethics Deputy Director, NHGRI Bioethics Core
4:30 – 5:30 pm	Ethical Issues in Genetic Research with Stored Samples	Dr. Sara Hull Director, Bioethics Core, Office of the Clinical Director, NHGRI
5:30 – 5:50 pm	Innovative Strategies for Vision Research to Treat Eye Diseases	Dr. Santa Tumminia Acting Director, NEI
5:50 – 6:00 pm	SURVEY	

**Bldg. 35A, Room 640**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 13<sup>th</sup> (Fri)</b>		
7:45 – 8:00 am	SURVEY	
8:00 – 9:00 am	Ophthalmic Genetics	Dr. Brian Brooks Clinical Director, Chief, Unit on Pediatric, Developmental & Genetic Ophthalmology, NEI
9:00 – 10:00 am	Genetics of Hearing Loss	Dr. Isabelle Roux Molecular Biology and Genetics Section, Otolaryngology Branch, NIDCD
10.00 - 10.30 am	BREAK	
10.30 - 11.30 am	Diabetes: Insights from Genomics	Dr. Lori Bonnycastle Staff Scientist, NHGRI
11.30 - 1.00 pm	LUNCH	
1:00 – 2:00 pm	Ethical issues arising from the application of genomics to the prevention and treatment of infectious diseases	Dr. Gail Geller Professor, Berman Institute of Bioethics and Department of Medicine, John Hopkins University Co-Principal Investigator, Johns Hopkins Center for Excellence in ELSI Research (CEER): Bridging Infectious Diseases, Genomics & Society (BRIDGES)
2:00 – 2:45 pm	How living and dying with malaria has shaped the human genome over thousands of years	Dr. Hans Ackerman NIH-Lasker Clinical Research Scholar, Investigator and Head, Physiology Unit Laboratory of Malaria and Vector Research, NIAID
2:45 – 3:30 pm	The Effect of Genetics in Tuberculosis Infection	Dr. Ray Chen Staff Clinician, NIAID
3:30 – 4:00 pm	BREAK	
4:00 – 4:45 pm	Proteomic and Genomic Approaches for Detection of Antimicrobial Resistance in Bacteria	Dr. John Dekker Lasker Clinical Research Scholar Chief, Bacterial Pathogenesis and Antimicrobial Resistance Unit, NIAID Director, Genomics Section, Microbiology Service, Department of Laboratory Medicine, NIH Clinical Center
4:45 – 5:00 pm	SURVEY	

**Personalized/Tailored Training at ICs**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 16<sup>th</sup>– 20<sup>th</sup> (Mon-Fri)</b>		
8:00 am – 5:00 pm	Personalized Training at ICs	

**Bldg 35A, Room 610**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 23 (Mon)</b>		
7:45 – 8:00 am	SURVEY	
8:00 – 9:00 am	Using Whole Genome Sequencing and Genomics to Understand the Clinical Impact of Human Sequence Variation	Dr. Drew Michael Associate Director, Molecular and Biochemical Diagnostics Laboratory, Children's National Health System Assistant Professor, Department of Genomics and Precision Medicine, George Washington University
9:00 – 10:00 am	Genetics of Craniofacial and Dental Anomalies	Dr. Janice Lee Clinical Director, NIDCR
10:00 – 10:30 am	BREAK	
10:30 – 11:30 am	Mosaicism	Dr. Les Biesecker Chief & Senior Investigator, Medical Genomics & Metabolic Genetics Branch, Head, Clinical Genomics Section, NHGRI
11:30 am-1.00 pm	LUNCH	
1:00 – 2:00 pm	Selected Current Molecular Treatment Approaches to Pediatric Neuromuscular Disorders	Dr. Payam Mohassel Senior Investigator, Neuromuscular & Neurogenetic Disorders of Childhood Section, NINDS
2:00 – 3:00 pm	Mitochondrial Genetics	Ms. Ellen Macnamara Certified Genetics Counselor, NHGRI
3:00 – 3:15 pm	BREAK	
3:15 – 4:45 pm	Biochemical Genetics	Dr. Nick Ah Mew Clinical Biochemical Geneticist Director, Inherited Metabolic Disorders Children's National Rare Disease Institute Associate Professor of Pediatrics The George Washington University
4:45 – 5:45 pm	Noninvasive Prenatal Genomics: The Vanguard of Genomic Medicine	Dr. Diana W. Bianchi Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development
5:45- 5:55 pm	SURVEY	



**Meet at The Gateway Visitor's Center, NIH**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 24<sup>th</sup> (Tue)</b>		
7:45 – 8:00 am	Survey on the bus	
8:00 am – 5.00 pm	<p>Field Trip- Children's National Health System 9 am- 12 pm 111 Michigan Ave NW, Washington, DC 20010</p> <p>MedStar Washington Hospital Center 12.30 pm- 4 pm 110 Irving St NW, Washington, DC 20010</p> <p>Survey on the bus</p>	

**Bldg. 35A, Room 640**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 25<sup>th</sup> (Wed)</b>		
7:45 – 8:00 am		SURVEY
8:00 – 9:00 am	NCATS Program: Genetic and Rare Diseases Information Center (GARD)	Ms. Michelle Snyder Certified Genetic Counselor, Operations Manager Genetic and Rare Disease Information Center, NCATS  Dr. Anne Pariser Director, Office of Rare Diseases Research NCATS
9:00 – 10:30 am	An Update Regarding Genetic Counseling and Testing for More Common Inherited Cancers	Ms. Tiffani A. DeMarco, MS, LCGC Licensed and Certified Genetic Counselor Director, Cancer Genetics Program Inova Schar Cancer Institute – Inova Fairfax Hospital
10:30 – 11:00 am		BREAK
11:00 – 12:00 pm	Cancer Genomics	Dr. Kathy Calzone, PhD, RN, AGN-BC, FAAN Research Geneticist Center for Cancer Research, Genetics Branch NCI
12:00 – 1:30 pm		LUNCH
1:30 – 3:00 pm	Genetics of Skin Disorders	Dr. Gabriele Richard Chief Medical Officer, GeneDx
3:00 – 3:30 pm		BREAK
3:30 – 4:30 pm	Genetics of Kidney Disorders	Dr. Asha Moudgil, FASN, FAST Associate Chief Professor of Pediatrics, GWU School of Medicine Medical Director, Kidney Transplant Children's National Health System
4:30 – 5:30 pm	NCBI Genetic Databases (ClinVar, dbGAP, GTR)	Ms. Adriana Malheiro Genetic Counselor, Director, NIH Genetic Testing Registry, NCBI/NLM
5:30 – 5:45 pm		SURVEY

**Bldg 35A, Room 640**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 26<sup>th</sup> (Thur)</b>		
7:45 – 8:00 am	SURVEY	
8:00 – 9:00 am	Harnessing the Power of “Big Data” to Improve Health and Healthcare	Dr. Nilay D. Shah Chair, Division of Health Care Policy & Research, Department of Health Sciences Research; Associate Professor of Health Services Research, Mayo Clinic, Rochester, MN
9:00 – 9:30 am	The Sustainable Development Goals, Global Health Strategies, and Newborn Screening	Mr. Mark Engman Senior Director, Public Policy and Advocacy, UNICEF-USA
9:30 – 10:15 am	Introducing and Sustaining Newborn Screening in a Developing Nation	Dr. Bradford L. Therrell Director, National Newborn Screening and Genetics Resource Center; International Newborn Screening Consultant
10:15 – 10:30 am	BREAK	
10:30 – 11:30 am	Challenges in setting up genetic services in low-resource settings	Dr. Carmencita D. Padilla Professor and Chancellor University of the Philippines Manila
11:30 am – 12:30 pm	Potential of Telemedicine in meeting health related SDG	Dr. Saroj K. Mishra Prof. & Head, Dept. of Endocrine Surgery; Nodal Officer SGPGI Telemedicine Program Sanjay Gandhi PG Inst. of Medical Sciences, Lucknow, India
12:30 – 12:45 pm	SURVEY	
12:45 – 1:45 pm	LUNCH	
1:45 – 2:30 pm	Medical Genetics Training Programs	Dr. Max Muenke Chief, Medical Genetics Branch, Director, Medical Genetics & Genomic Medicine Training Programs, NHGRI
2:30 – 3:30 pm	Presentation by Candidates (4)	
3:30 – 3:45 pm	BREAK	
3:45 – 5:45 pm	Presentation by Candidates (8)	

**Bldg 35A, Room 640**

	<b>Topic</b>	<b>Speaker</b>
<b>Sept. 27<sup>th</sup> (Fri)</b>		
8:00 – 9:00 am	Presentation by Candidates (4)	
9:00 – 10:00 am	Presentation by Candidates (4)	
10:00 – 10:30 am		BREAK
10:30 – 11:30 am	Presentation by Candidates (4)	
11:30 – 12:30 pm	Presentation by Candidates (4)	
12:30 – 1:30 pm		LUNCH
1:30 – 2:30 pm	Presentation by Candidates (4)	
2:30 – 3:30 pm	Presentation by Candidates (4)	
3:30 – 4:00 pm		BREAK
4:00 – 5:30 pm	Graduation and Closing Remarks	Program Coordinators- Ms. Manjit Kaur Program Administrator, NHGRI  Dr. Max Muenke Director, Medical Genetics & Genomic Medicine Training Program; Senior Investigator and Chief, Medical Genetics Branch, NHGRI

**Sept. 28<sup>th</sup>** All candidates must depart

## **International Summit in Human Genetics and Genomics, 2019**

The International Summit in Human Genetics and Genomics was hosted by NHGRI on the NIH campus, from August 28th –September 28th, 2019. It was the fourth of the 5- year (2016-2020) trans-NIH initiative to advance genetics and genomics in research and medicine, in low to middle income countries (LMIC; World Bank). Based on last year's success, two additional ICs (NCATS, NIA) participated this year, for a total of 15 ICs, including FIC, NCI, NEI, NHGRI, NHLBI, NIAID, NICHD, NIDA, NIDCD, NIDCR, NIMHD, NINDS and NINR.

As mortalities from more common diseases and disorders decline, genetic disorders and congenital birth defects consume a disproportionate level of resources allotted to health care. Many LMICs lack expertise in genetics and genomics. This impacts the required training for the provision of care and contributes negatively to the welfare of these nations. The International Summit aims to alleviate these issues by filling the knowledge gap in human genetics and genomics.

With generous support from ICs at NIH and donations made to the Foundation for the NIH (FINH) by ACMG, ASGCT, ASHG, Mayo Clinic, Sanford Health and Sarepta Therapeutics, 34 candidates from 24 countries (refer to world map on reverse side) attended the Summit. Participants included research scientists (6), physicians (17) physician/scientists (3), physician/PhD(c) (2), physician/counselor (1), dentist/scientists (2), nurse/scientist (1), counselor (1) and clinical psychologist (1).

The curriculum included 11.5 days of didactics in genetics/genomic research and medical genetics; 5 days of mentoring in the participants' area/s of interest; 3 days of field trips. Over 70 speakers delivered 70+ lectures (ISHGG 2019\_Agenda), including on new topics (genomics of malaria, TB, mental illness, substance use, etc.). The training included hands-on workshops in bioinformatics, grant writing, genetics clinic and patients. The field trips included visits and lectures at academic and commercial institutions, that provide clinical and laboratory services (Children's National Health System, GeneDx, Johns Hopkins University, Kennedy Krieger Institute, Maryland Public Health Laboratories, MedStar Washington Hospital Center, National Center for Advancing Translational Sciences, NIH Clinical Center, NIH Intramural Sequencing Center). These visits informed the participants of the spectrum of experts, infrastructure and systems involved in the provision of genetic services and testing. Approximately one third of participants identified the week of personalized training as their favorite part of the Summit. Grant writing, bioinformatics workshop and the patient panel were additional favorites of the Summit. Several patients shared their insights, struggles and continuing needs, because of the genetic diseases affecting them or their family members. Participants described the Summit as "visionary", "life changing", "amazing" "career enhancing" and "an opportunity to interact literally with the world."

To measure outcomes, we assessed prior knowledge, learning and interest through daily pre- and post-curriculum surveys. The results were consistent with those of previous years which describe the Summit as a unique learning opportunity for participants and speakers, and they strongly encouraged its continuance. All activities were rated as imparting knowledge and important to include in next year's summit.

The 2018 annual outcome (2016/17/18 batches) has been remarkable (ISHGG 2018\_Annual Outcome). Participants established collaborations (64) with investigators at NIH, other US-based academic institutions and amongst themselves; Published articles (177, in various stages), in their field of expertise and related to genetics; Wrote/received grants to/from NIH or other funding agencies (53); Initiated new research and/or clinical projects (38) and influenced the course of ongoing research projects (49). Our assessment of outcomes will continue for 5-years with every cohort.

Based on the survey feedback (2019) and 2018 outcomes, the Summit has made good progress in achieving its goals and is in popular demand. Thus, in 2020, we hope to host up to 40 candidates. This however will only be possible with support from our Institutes and Centers at NIH and the FINH.

# Fourth International Summit in Human Genetics and Genomics

National Institutes of Health, Bethesda, Maryland, August 28 - September 28, 2019

## Mexico



Jorge Eduardo Ortiz Panozo



Bethania López

## Ecuador



Arianne Llamas Paneque

## Peru



Solange R. Paredes Moscoso

## Romania



Radu Pirlog

## Turkey



Yeliz Guven



Meltem Ece Kars



Ilknur Yeşilçinar

## Mali



Abdoulaye Bocoum

## Ghana



Samuel Agyei Wiafe

## Nigeria



Henrietta Ifechukwude Monye



Olukayode O. Akinmola



Lukman Adewale Alli



Sanusi Abubakar



Oluyomi Okunola

## Egypt



Inas Sayed

## Sudan



Tyseer Alabd Elisiddig Hag Alamin

## Democratic Republic of Congo



Kizito Mosema Be Amoti

## Zimbabwe



Kudakwashe Mhandire

## Tanzania



Theophylly L. Mushi

## Eritrea



Yishak Gebrekidan Weldemichael

## Sri Lanka



Givani Amarakoon

## India



Deepti Mutreja



Lekshmi S Nair



Sakshi Yadav

## Bangladesh



Enamul Haque Chowdhury

## Mongolia



Naranchimeg Baatar

## Pakistan



Muhammad Iqbal

## Nepal



Pratiksha Gyawali

## Myanmar



Aye Kyawt Khant

## Vietnam



Luong Hoang Long

## Philippines



Ma-Am Joy R. Tumulek

## Malaysia



Norita Hussein



Shing Ying Tiong