## GGMC FY2023 ANNUAL REPORT

GLOBAL GENOMIC MEDICINE COLLABORATIVE







#### **GLOBAL GENOMIC MEDICINE COLLABORATIVE OVERVIEW**

We are pleased to see a continued period of growth and structural changes in 2023 that will foster future successes and achievements of the organization that continue to enhance activity and enthusiasm amongst our growing membership.

This year, Ms. Tejinder (Teji) Rakhra-Burris, MA, was formally appointed as President & CEO of GGMC. Under her leadership, the GGMC Secretariat convened in May 2022 for their second "Advance" — a day-long retreat that brought the typically virtual team together in-person to maximize the strengths of our team, address current and foreseeable challenges, and set a strategy for the Secretariat to successfully implement the goals and activities of the organization.

During 2023, GGMC initiated the 2022 structural changes to assemble three GGMC core committees — Workforce & Training, Policy & Advocacy, and Diversity, Equity & Inclusion — appointing co-leads for each, and initiating a call for Early Career Investigators (ECIs) to work closely within these committees, providing hands-on learning and mentorship.

This year was pivotal in refining our overarching goals through involvement with the World Health Organization (WHO) Technical Advisory Group on Genomics (TAG-G) developed from the 2022 WHO Science Council report on Accelerating access to genomics for global health. We are honored that three GGMC senior leaders were chosen as representatives of their global region. Congratulations to Marc Abramowicz, Michele Ramsay, and Gabriela Repetto! Additionally, we were very appreciative of the opportunity to join in the TAG-G first meeting's open forum, with other organizations in genomics and global health, to provide input on opportunities for WHO contributions to accelerate access to genomic technologies for global health and how WHO can contribute to the work of these organizations.

Both programs within GGMC, the Global Genomic Medicine Consortium (G2MC) and the International Health Cohorts Consortium (IHCC) have made significant contributions in 2023 to genomic medicine and global health through projects and initiatives, which are detailed further in this annual report. In particular these activities, the involvement with the WHO TAG-G, and a joint meeting of our Consortia's Executive Committee in mid-October 2023, the GGMC will prioritize its broad focus in three areas:

- Building the next generation of genomic leaders through a commitment to providing mentorship and project leadership opportunities to our **Early Career Investigators**
- Enabling Advocacy within our members to engage with their country and regional health care providers, government health officials, and others involved in the delivery of healthcare to identify needs and develop relevant policy
- Understanding what *Diversity, Equity & Inclusion* means to our members, and fostering a supportive environment in which colleagues from diverse backgrounds and demographics can excel within our organization and within the global genomic medicine community

The activities initiated in 2023 have positioned GGMC for substantial growth and collaborative opportunities as we enter 2024. We remain committed to transparency, diversity, inclusion and equity in all that we do, and look forward to the opportunities and challenges ahead. It is with much gratitude that we thank our members, leadership team, partners, funders and sponsors for another successful year.

Chair of the BoD, GGMC Vajira H. W. Dissanayake



#### Mission

integration efforts worldwide







#### Diversity, Equity and Inclusion (DEI)

We are committed to diversity, inclusion and equity in our mission. The GGMC is a supportive environment in which colleagues from diverse backgrounds and demographics can excel.

We see our community as equal in terms of stature and opportunities to contribute. We bridge language barriers, increase opportunities for funding, partnerships, and participation from all of the members and stakeholders we serve.

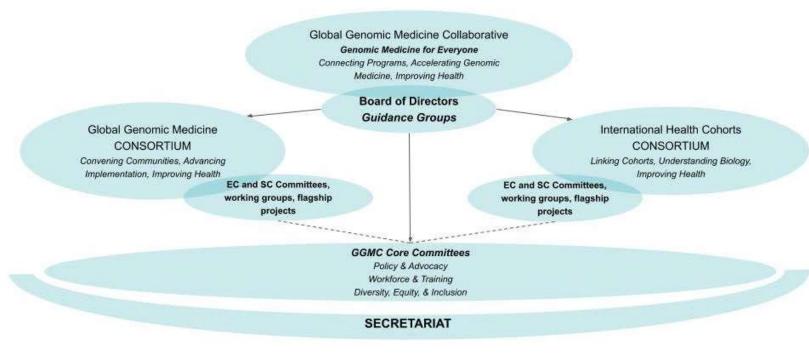


Genomic Medicine for Everyone





#### Global Genomic Medicine Collaborative



#### **Our Core Committees**









## GLOBAL GENOMIC MEDICINE CONSORTIUM CO-CHAIRS OVERVIEW

The G2MC is creating a community of global leaders dedicated to advancing genomic medicine implementation in clinical care, especially in low- and middle-income countries (LMICs). To further this mission, we have continued to expand the diverse leadership of G2MC governance in 2023. In January, Bruce Korf (USA) was appointed as G2MC Interim Co-Chair for 2023, as he took the place of former and founding G2MC co-chair, Geoffrey Ginsburg (USA), who completed his term at the end of 2022. In September, Bernard Esquivel (Canada/Mexico) stepped up as interim co-chair to cover for Catalina-Lopez Correa (Canada) during her medical leave. Last quarter also saw the nomination of Michelle Bishop (UK) joining the Steering Committee as co-lead for the newly created Resource Center Working Group and Dame Sue Hill (UK) joining the Executive Committee.

In March 2023, we announced the restructuring of G2MC's functional groups as a result of the <u>G2MC Strategic</u> <u>Plan</u> to better align with our priorities. This was followed by an update in May 2023 to provide increased clarity of the functions of the groups and consistency in naming across GGMC's consortia. The Early Career Investigator (ECI) Affinity Group is now a part of the Workforce & Training Core Committee at the GGMC level. Similarly, the Diversity, Equity and Inclusion (DEI) Subcommittee is now integrated into the GGMC DEI Core Committee, as described previously in this report (GGMC section). G2MC now has four working groups and two flagship projects. You can view these changes on the <u>G2MC website</u>. Three working groups were newly created and have already produced innovative ideas and action plans this year, on top of the continuous progress of both existing flagship projects, which are detailed further in this report.

In October, G2MC held a successful 7th International Conference in Geneva, Switzerland. We are grateful for the 18 months of planning provided by the Scientific Planning committee composed of the 2 conference co-chairs, Marc Abramowicz and Vajira Dissanayake, several members from the Steering Committee and G2MC Early Career Investigators (ECIs,) and by the logistics group composed of the local host Marc Abramowicz and his team from the University Hospital of Geneva, the local event planner, Symporg, and the G2MC Secretariat. Each conference continues to grow in diversity and attendance, especially with participants from LMICs, and we are pleased to continue to cultivate our ECI involvement and provide our next generation with guidance and opportunities, setting them up for success. We are excited to continue building on this momentum to foster the growth of future leaders in genomic medicine implementation. This effort includes the involvement of ECI representatives on all of our G2MC functional groups and establishing educational and mentorship opportunities as part of our core functions.

Moving forward, we must continue to train and expand our workforce, mentor our future leaders, define best practices, advance our approaches, and raise awareness about the importance of genomic medicine implementation throughout the world.

Sincerely,

G2MC co-chairs

George P. Patrinos

Bruce Korf

Bernard Esquivel

#### **MISSION:**

To leverage and nurture global expertise, create practical, real-world solutions and disseminate knowledge for implementing Genomic Medicine

#### **PURPOSE:**

An international community formed to advance the implemination of Genomic Medicine and improve medicine for all





#### **G2MC BY THE NUMBERS:**





Early Career Investigators (ECIs) active within G2MC activities, with 3 ECIs co-leading functional groups

#### **OCTOBER 2023 GENEVA CONFERENCE:**



225 Registrants 49 Countries 33 LMICs



23 Speakers 13 Countries 8 LMICs



32 ECI Presenters 16 Countries 11 LMICs



#### **PROGRAM HIGHLIGHTS:**











#### WORKING GROUPS

#### **G2MC Membership**

- Gathered data from our members through the <u>Join Us Form</u>
- Building our membership database
- Defining G2MC member requirements, values and benefits

#### **G2MC Resource Center**

- Kicked off during the 7th Conference in October 2023
- Reaching out to all G2MC functional group co-leads
- Surveying the G2MC members to understand their needs and resources
- Building the database starting with Family Health History artifacts as a pilot

#### **G2MC Implementation Projects**

- Creating the project proposal template form
- Gathering information on what projects our members are doing or would like to do, their challenges, and what kind of support G2MC could provide

#### FLAGSHIP PROJECTS

#### **G2MC Rare Genetic Disorders**

- Completion of the pilot project of exome sequencing for the diagnosis of rare diseases in 6 clinical sites in LMICs
- Pilot results presented during the International Conference on Birth Defects and Disabilities in the Developing World (ICBD), in March 2023 in Santiago, Chile
- Pilot results being submitted for publication in various journals, including a special issue of Frontiers in Genetics
- Scaling up the project to about 20 sites with funding opportunities from different sources

#### **G2MC Family Health History (FHH)**

- Creating cooperatively within about 10 countries a universal/generalizable FHH project plan, including validating a FHH questionnaire for Hemoglobinopathy identification and prevention
- Cases for support and grant applications are part of the next steps



## INTERNATIONAL HEALTH COHORTS CONSORTIUM CO-CHAIRS OVERVIEW

We are pleased to present the International Health Cohorts Consortium (IHCC) Annual Report for 2023. The IHCC is a global network of cohorts that are committed to improving the health of populations around the globe, especially those in low- and middle-income countries (LMICs). The IHCC has made significant progress over the past year in enhancing cohort studies, fostering collaborations among its members, and promoting workplace development among all members.

We modified our name in 2023 to the International Health Cohorts Consortium to enhance our outreach and assistance for new, nascent cohort members, especially from LMICs, low-resource settings (LR) and under-represented (UR) populations around the world.

In 2023, we continued to expand the diverse leadership of IHCC governance with Nicky Mulder (S. Africa), Nicki Tiffin (S. Africa) and Ricardo Verdugo (S. America) joining the Executive Committee, and Nahla Afifi (Qatar), Sarah Bauermeister (UK), Arash Etamadi (US) and Aleksandra Gentry-Maharaj (UK) joining the Steering Committee.

The IHCC is continually conducting a series of surveys to assess the needs and interests of its cohort members. Recently, along with the UK Biobank, Genomics England and others, the IHCC sent a survey to our members to catalog and support bold, cross-cohort project opportunities, prioritized by their potential to impact global health. These surveys will help us to better understand how the IHCC can support its members and to develop new programs and resources to meet those needs.

Two of IHCC's working groups, 1) Policy & Systems, and 2) Training & Workforce Development, have been elevated within the Global Genomic Medicine Collaborative (GGMC) organization to serve both consortia programs, IHCC and the Global Genomic Medicine Consortium (G2MC.) With common missions and objectives for both consortia, these new workgroups will provide members with valuable educational opportunities and global policy insights going forward. One of the highlights of this cross-consortia consolidation is the newly-branded GGMC (formerly IHCC) Monthly Educational Webinars that explore new methods for applying genomic medicine approaches to both cohort science and clinical implementation.

One of IHCC's strategic goals is to facilitate collaborations between cohorts in LMICs and other countries, for example with cohorts from Uganda and Chile joining the Metabolomics Pilot Project in 2023. With the IHCC providing seed-funding to support these cross-cohort collaborations, several of our IHCC Pilot Projects have published important scientific findings and secured additional funding to expand the number of participating cohorts and continue their impactful research.

The IHCC is committed to improving global health through the enhancement of cohort studies, the fostering of collaborations, and the promotion of workplace development. We are proud of the progress that we have made in the past year, and we look forward to continuing to work with our partners to strengthen the health of populations around the world.

Sincerely,
IHCC Co-Chairs
Geoff Ginsburg
Peter Goodhand
Michele Ramsay

#### **PURPOSE:**

An international community formed to advance the implemination of Genomic Medicine and improve medicine for all

#### **MISSION:**

To leverage and nurture global expertise, create practical, real-world solutions and disseminate knowledge for implementing Genomic Medicine





#### **PROGRAM HIGHLIGHTS:**



#### Pilots transitioning to

#### Sustainable Projects

Preliminary pilot-phase data/publications led to external funding that extends scope of IHCC Pilot and ability to add LMIC cohorts:

- Metabolomics (Hakonarsson et.al.)
- Covid-Mental Health (Smoller, Bauermeister, Brunoni)
- OPICO (Sheikh)
- BMI-Cancer (Hughes)



#### **Publications**

## 7 new in 2023, with 9 LMICs participating

- Incident cancers attributable to using opium and smoking cigarettes in the Golestan cohort study.
- Opioid medications: an emerging cancer risk factor?
- Trans-ethnic polygenic risk scores for body mass index (editorial)
- Trans-ethnic polygenic risk scores for body mass index: An international hundred K+ cohorts consortium study (research paper)
- Trans-ethnic genomic informed risk assessment for Alzheimer's disease: An International Hundred K+ Cohorts Consortium study
- The Associations of Selenoprotein Genetic Variants with the Risks of Colorectal Adenoma and Colorectal Cancer: Case–Control Studies in Irish and Czech Populations
- Separating the effects of early and later life adiposity on colorectal cancer risk: a Mendelian randomization study



## Biobank Training Seminars (in Collaboration w/ Qatar Biobank)

7 hours of video training
Live viewers from 29 countries (with
many more on YouTube!)

- Biobank Design Strategy
- Planning and Implementation
- Quality Standards & Accreditation
- Communication and Recruitment
- Biobank IT Systems
- Biobanking Services



#### **Educational Webinars**

10 Webinars live-streamed, with speakers from Australia, Canada, Singapore, UK and the US.



#### Six Cohorts Added in 2023

- Connect for Cancer Prevention Study Cohort (US)
- Colorado Center for Personalized Medicine Biobank (CCPM) (US)
- GARBH-INI: interdisciplinary
   Group for Advanced Research on
   BirtH outcomes DBT India
   Initiative (India)
- ECRAID Perpetual Observational Studies (cross-Europe)
- Data4Life Cohort (India)
- The Saudi Biobank Project



## IHCC BY THE NUMBERS:

- 70 cohorts listed in IHCC Cohorts Atlas
- 34 million+ unique participants
- million participants with biospecimens avaliable
- million genomic datasets avaliable
- 6 new cohorts
- new cross-cohort project proposals



# GLOBAL GENOMIC MEDICINE COLLABORATIVE: REVENUE AND EXPENSES

TOTAL REVENUE	\$861,231
Program Grants	\$805,569
Sponsorship	\$37,000
<b>Donations</b>	\$1,6805
Other Income	\$1,857

<sup>\*</sup>Program grants include realized and awarded, in process

#### TOTAL EXPENSES \$848,020

\*Allocation for benefit of LMIC partners through direct funding or procurement of services \$212,916

Sponsored projects distribution \$164,511

IHCC \$154,583

G2MC \$9,928

#### NUMBER OF LMICs INVOLVED IN SPONSORED PROJECTS

IHCC (8 projects) 5 G2MC (1 project) 6





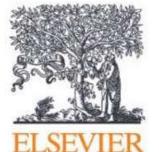
## OUR PARTNERS, SPONSORS, AND FUNDERS







































A special thanks to the voluntary leadership of GGMC and its consortia who have given their time and expertise, as well as financial support, to the organization.









### 2024 RESOLUTIONS

#### G2MC

Through the leadership of the G2MC cochairs George P. Patrinos, Bernard Esquivel, Catalina Lopez-Correa and newly appointed Gabriela Repetto, G2MC will focus on the following in 2024:

- Sustainability: procure programmatic support and resources for activities by following specific actions defined in 2023 and new initiatives
- Resource Center: building the genomic medicine database and expand its content
- Membership and Engagement: continue to grow the membership and leadership diversity, as well as develop member's benefits and values
- Flagship Projects: scaling up the Rare
  Diseases project, supporting Family
  Health History cooperative project,
  seeking funding sources, showcasing new
  flagship projects and collaboration
  opportunities for implementation solutions
- Planning the 8th International Conference to be held in early 2025

### GGMC

Through the foundational activities in 2023 - initiated with the development of three Core Committees, and concluded with a call to action from the WHO Science Council's assembly of its Technical Advisory Group on Genomics, GGMC will enter 2024 to activate the three core committees to work with a core group of leadership to develop the roadmap for achieving the goals of the Cape Town Declaration:

- Build the next generation of genomic leaders through a commitment to providing mentorship and project leadership opportunities to our Early Career Investigators
- Enable Advocacy within our members to engage with their country and regional health care providers, government health officials, and others involved in the delivery of healthcare to identify needs and develop relevant policy statements of need
- Through understanding what Diversity,
  Equity & Inclusion means to our
  members, foster a supportive
  environment in which colleagues from
  diverse backgrounds and demographics
  can excel within our organization and
  within the global genomic medicine
  community

The IHCC plans to achieve the following goals in 2024:

- Secure funding and plan workshops for cross-cohort research on Climate & Health
- Create and implement an international "Cohorts to Clinics Conference" in collaboration with Precision Health Research SIngapore (PRECISE); August, 21-23, 2024 in Singapore
- Explore the requirements for a Pharmaceutical consortia working with IHCC Cohorts

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