

Hello everyone,

Welcome to our first ICPGC Newsletter. We hope that all of you are safe and well, wherever in the world you live.

The ICPGC Governance Council will be sending regular newsletters to update members on consortium projects, research outputs, meetings, working groups and more. If you have any updates or research news that you want to share, please send these through to [info@icpgc.org](mailto:info@icpgc.org), so they can be included in the next newsletter.

ICPGC Governance Council

P.S If you have friends/family members/ colleagues who would like to receive this Newsletter please let them know that they can subscribe [here](#).

## **PROJECTS – in development**



### **CP Commons.**

The CP Commons is ready for data uploads and has received human research ethics approval from the University of Sydney to hold genomic and clinical data from research cohorts. For more information, please contact Yana Wilson (Cerebral Palsy Alliance) [ywilson@cerebralpalsy.org.au](mailto:ywilson@cerebralpalsy.org.au).



### **ICPGC Flagship project.**

We are in the early stages of developing our flagship project for the ICPGC, where we will be aggregating whole exome and whole genome datasets for large analyses. Do you have research cohort data that you would be willing to contribute? Would you like to be an investigator on this project? Help us develop the largest aggregation of genome data from individuals with CP, so that we may unlock more clues about the underlying neurobiology of CP. For more information about this ground-breaking study, please contact the team [info@icpgc.org](mailto:info@icpgc.org).



### **Polygenic risk in CP.**

We are aiming to aggregate new and existing SNP array data to calculate polygenic risk for CP and determine their predictive value. For more information and to be involved in this study, please get in contact with Mark Corbett (University of Adelaide) [mark.corbett@adelaide.edu.au](mailto:mark.corbett@adelaide.edu.au)



### **ClinGen GCEP.**

We are working with ClinGen to establish a CP Gene Curation Expert Panel (GCEP). We are currently looking for biocurators who can help collect and document the evidence of the genes we are aiming to curate, and then synthesise the information for the experts to review. For more information, please contact Andres Moreno de Luca (Geisinger) [amorenodeluca@geisinger.edu](mailto:amorenodeluca@geisinger.edu).



### ***Do you have an idea for a new ICPGC project?***

*Please contact us to discuss [info@icpgc.org](mailto:info@icpgc.org)*

## PROJECTS – completed



### **Common Data Elements for Genomic Studies of CP**

The Phenotype working group recently completed their first piece of work, identifying common data elements for the genomic studies in CP and the CP Commons. These are now available on the website [here](#) and the paper is under development.

## MEETINGS

### **2021 4<sup>th</sup> ICPGC Meeting – October 22 and 23**

We are pleased to announce our 2021 ICPGC annual meeting. The virtual meeting, which will be held across two days and in conjunction with the [CP-NET Science and Family Day](#), will be held on both Friday October 22 and Saturday October 23 at 6:00am-9:00am (Toronto, EDT). The meeting is being kindly supported by CanChild, the McLaughlin Centre and CP-NET. We are looking for two volunteers from the consortium membership to help the organising committee. If you are interested, please contact Richard Wintle <mailto:rwintle@sickkids.ca>



We will distribute more information about the meeting shortly, including a call for abstracts and an agenda.

### **2022 AusACPDM/IAACD/5<sup>th</sup> ICPGC Virtual Meeting**

We are pleased to announce a “Save the Date” for a 2022 ICPGC meeting at the combined [AusACPDM/IAACD](#) meeting in Melbourne. The ICPGC meeting is set for Tuesday, March 1 at 9:00am-1:00pm (Melbourne, AEDT). We are seeking four people to volunteer for the organising committee. If you are interested in helping organise this virtual/in-person meeting, please contact Michael Fahey [mfahey@monash.edu](mailto:mfahey@monash.edu)



## RECENT RESEARCH HIGHLIGHTS



### **New CP Genomics study in DMCN**

Please see links to a recent publication and podcast from Jason Carmel and teams from the Weinberg Family Cerebral Palsy Centre and Columbia University Irving Medical Centre. This research aims to identify which children with CP should undergo genetic testing.

Read more [here](#)// Listen to the podcast [here](#)

## ICPGC GENERAL UPDATES

### **Governance Council Updates**

The ICPGC Governance Council welcomed our newest member, Dr. Charles Steward (Congenica, UK) in April. As some of you may be aware, Charlie is a genomic scientist who has worked on the human genome for more than 27 years. He is also the father of two young children with CP, and thus additionally brings a much-needed parent and patient advocate perspective to the ICPGC Governance Council.

Prof. Jozef Gezc has rotated into the Chair of the Governance Council position. Thank you to Dr. Michael Kruer, who held the position for the last four years, since the inception of the ICPGC in March 2017.

The current ICPGC Governance Council members are: Jozef Gezc (University of Adelaide, Australia), Gareth Baynam (WA Health, Australia), Michael Fahey (Monash University, Australia), Andres Moreno De Luca (Geisinger, USA), Charles Steward (Congenica, United Kingdom), Richard Wintle (CP-NET, Canada), Yana Wilson (Cerebral Palsy Alliance, Australia) and Changlian Zhu (Gothenburg University, Sweden/Zhengzhou University, China).



### **How do I become a member of the ICPGC?**

Anyone with an interest in genomics and cerebral palsy can be a consortium member. If you have received this newsletter, consider yourself a consortium member! Please pass this newsletter onto those who you think may want to join the consortium, and they can contact us at [info@icpgc.org](mailto:info@icpgc.org) to become a member and stay connected.



### **How can I contribute as an ICPGC Member?**

As well as joining projects and participating in meetings, we currently have a number of working groups that need people to join and contribute to: Bioinformatics, Phenotype, CP Commons and Communications. Please contact [info@icpgc.org](mailto:info@icpgc.org) if you would like to participate.