

NeuroGAP Newsletter

August 2024

NEURODEV:

South Africa: The NeuroDev team has begun returning negative findings to South African participants enrolled in the study. This has been initiated for the pilot phase of the project and participants have been greatly appreciative about the contact and update. With permission from the families, their child's managing clinician has also been updated about the findings, enabling informed decisions regarding future genetic testing and management considerations.

Congratulations to Nolene Chetty and Angelique Diedericks for their excellent research related to the NeuroDev study:

- Nolene Chetty received a distinction for her thesis on "Experiences of Stigma in South African Families with Neurodevelopmental Disorders"
- Angelique Diedericks published her master's work on "Parental Perspectives Regarding the Return of Genomic Research Results in Neurodevelopmental Disorders in South Africa: Anticipated Impact and Preferences" in the Journal of Community Genetics (<https://link.springer.com/content/pdf/10.1007/s12687-024-00723-w.pdf>).
- Zandre Bruwer has also recently presented on the return of individual research findings during a webinar to the South-African Genetic Counselors Association as well as to the Genetic Department at the University of Cape Town.

Nairobi:

The NeuroDev Nairobi project ended on July 31st, 2024, with 170 (61% of target) participants from 101 families enrolled. The case and case families recruited were 128 and comprised 59 (74% of target) cases, 4 siblings to cases, 48 mothers, and 17 fathers culminating in 1 quad, 15 trios, 34 dyads, and 8 single cases. The controls recruited are 42 (60% of target). Most of the participants, including all controls were recruited through the community. Only 3 case families were recruited through Njathaini Primary School in Ruaraka Sub-county. The general observation was that families were hesitant to participate because of blood draws and the taking of photos.

NeuroGAP-Psychosis:

NeuroGAP Psychosis II Launch

Congratulations to all teams involved in the launch of NeuroGAP-Psychosis II. This study will build on the original NeuroGAP-Psychosis I study by implementing new phenotypic tools and expanding on previous data collection. In September 2024, NeuroGAP-Psychosis II will commence recruitment at Mathari National Teaching and Referral Hospital in Nairobi, Kenya by the Aga Khan University under the leadership of Dr. Lukoye Atwoli. Additionally, in November 2024, recruitment is projected to begin at Victoria Mxenge Hospital in Durban, South Africa by the University of KwaZulu-Natal under the leadership of Dr. Bonga Chiliza.

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NeuroGAP-Psychosis Dissemination Meeting, August 2nd, 2024:

In collaboration with Academic Model Providing Access to Healthcare (AMPATH), the NGAP research teams out of Moi University and Moi Teaching and Referral Hospital (MTRH) located in Eldoret, Kenya provided progress updates for ongoing NeuroGAP projects which included capacity development, ethics considerations and tool validation among others. HSPH team members Dr. Manasi Sharma (Research Scientist) and Research Coordinators Molly Pomeroy and Zachary Schwartz attended and presented on Trauma and PTSD in Kenya and Uganda: Prevalence and Protocol Feasibility of the NeuroGAP-Psychosis PTSD Follow-up Study. Professor Lukoye Atwoli (Professor and Dean of Medical College East Africa) presented on the study rationale and design of the NeuroGAP psychosis study and the site project manager, Freddie Ochieng, discussed the patient experience upon collaboration with his research team.



Caption (from top left to bottom right): Freddie (MTRH Project Manager) presents at the dissemination meeting about the Participant experience and the interviewing process, Professor Lukoye with collaborators and research team, Dr. Manasi Sharma with research team (both HSPH and MTRH) and Professor Lukoye presents on New studies (Supplement and PTSD)/The future of NeuroGAP and the possibilities ahead

Congratulations to Zahra Morawej, Anne Stevenson, and Manasi Sharma on publishing three papers from the NeuroGAP-Psychosis study:

- Morawej et al. [Experiences of trauma and psychometric properties of the Life Events Checklist among adults in Uganda.](#)
- Stevenson et al. [Relationships between trauma types and psychotic symptoms: A network analysis of patients with psychotic disorders in a large, multi-country study in East Africa - ScienceDirect.](#)
- Sharma et al. [The cumulative impact of trauma, chronic illness, and COVID-19 stress on mental health in a case-control study of adults with psychotic disorders in Ethiopia.](#)

Hats off to Anne, Manasi, and Engida Girma for having 5 abstracts accepted to the ISTSS Annual Meeting. Special congratulations go to Engida who won the ISTSS Underrepresented Scholars Award. This award is given to early career trauma professionals from around the world who identify as Black and/or Indigenous, on the basis of their potential contribution to the field of traumatic stress in research, teaching, clinical service, policy, or advocacy.

Anne traveled to Gqeberha, South Africa to Nelson Mandela University in May to meet with Prof. Zuki Zingela and Marine Beltran. Anne presented on results from the NeuroGAP-Psychosis study and on trauma exposure in the South African sample. There was a great discussion after with clinicians and community members in the region on how the results squared with their own experiences.



Anne presents to faculty, staff, and community members at Nelson Mandela University in Gqeberha, which was followed by a Q&A and discussion with the group.

NeuroGenE:

The AEWG extends its heartfelt congratulations to Prof. Adamu Addissie for delivering an authentic and captivating keynote presentation at the Oxford Global Health & Bioethics International Conference, held at Oxford University in July 2024. His talk, titled "Think 'Global,' Act 'Local' – Ethics of Equitable Global Partnerships," resonated deeply with attendees and has now been made available on the workshop website. You can watch the presentation here: <https://youtu.be/8twRqwk-g0g?si=0aH8NeB1IQ1epZdn>



At the same event, the AEWG successfully hosted a workshop titled "Ethics, Neuropsychiatry, and Genomics/Genetics Research." The session showcased various empirical ethics research projects coordinated by the AEWG and the NeuroGenE team, along with their collaborative efforts that have led to two significant offshoot projects. The presentations were followed by a dynamic and engaging panel discussion. Participants were particularly intrigued by the AEWG's involvement in two ground breaking studies in Africa. A lively debate ensued as attendees sought to understand how the AEWG's embedded approach impacted project implementation, how they provided meaningful ethical guidance, and whether researchers had acted on the experts' recommendations.





Over the summer, NeuroGenE had the pleasure of hosting Jordan Freeman from Johns Hopkins University. Jordan is currently pursuing a DPhil project focused on understanding meaningful participation in mental health research for young people, with a particular emphasis on youth in Africa (specific countries are yet to be determined). During her time with us, Jordan engaged in discussions with team members involved in several of our key projects, such as NeuroGAP, Fogarty, EMDIYA, and AfOx, as well as other initiatives within the Department of Psychiatry that focus on youth participation and advocacy in mental health.

GINGER:

Graduation Workshop May 2024: The GINGER program celebrated the graduation of its second cohort of fellows in Tulbagh, South Africa, from May 27th to May 29th. The graduation included a three-day workshop, during which fellows participated in a 1.5-day interactive session on negotiation and adaptive leadership skills led by Ons Ben Abdelkarim, a negotiation coach from the Harvard Kennedy School. Rocky Stroud, Kim Hook, and Dr. Akena also presented on budget, grant, and project management best practices. GINGER alum Lerato Majara presented her work as a post-doctoral scholar in Alicia Martin's lab, focusing on NeuroGAP study data, and Justin McMahon provided a data access refresher. It was not all work with no fun, though; fellows, GINGER Team Members, and workshop speakers enjoyed a ziplining adventure over the hills in Tulbagh as a celebratory team outing to mark their graduation accomplishment.

Virtual Classrooms: Cohort II Fellows completed their final semester of virtual classrooms, which included a three-session workshop on grant writing, an introduction to Sequence Data (covering foundational knowledge, quality control, and rare/structural variant testing), topics in fine mapping and heritability, as well as a guest lecture by Dr. Jordan Smoller.

Other News: Engida Girma will receive the Underrepresented Scholars Award from the International Society for Traumatic Stress Studies (ISTSS) in September 2024 (see more information below). Patricia Kipkemoi and Mary Mufford's paper, "Evaluation of the Psychometric Properties of the UBACC Questionnaire in a Multi-Country Psychiatric Study in Africa," mentored by Kristina Korte, has been accepted for publication in *Comprehensive Psychiatry*.