

International Alliance of Academies of Childhood Disability

QUARTERLY NEWSLETTER

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In this newsletter you can expect:

EAACD raising autism awareness

General IAACD Business

IAACD Committee Updates

Upcoming Events & Member Organization Updates

THE EAACD JOINS PROF. ELIZABETH BUKUSI TO RAISE AUTISM AWARENESS

Day 1 - The Journey Begins

Despite careful planning to leave Nairobi at 2 pm, delays struck immediately. Two team members were held up by urgent paperwork, forcing one to drive down later that evening. These unexpected events mirrored caring for a special needs child—no matter how well you plan, life happens unexpectedly. Three climbers reached Naro Moru by evening, with the fourth arriving late after Google Maps led them astray in rural areas. After dinner and tea, we prepared for the challenges ahead, knowing this would be our last comfortable night.

Day 2 - The Mountain Beckons

Morning brought gear inspection—no cotton items allowed at altitude, as they become deadweight when wet. Like preparing for special needs care, we needed resilience, patience, kindness, goodness, and self-control. After final showers (our last for five days), guides checked equipment and organized transport to Naro Moru gate. We discussed our mission: raising autism awareness during April's Autism Awareness Month. Efficient wardens processed our entry, inspecting luggage to prevent single-use plastics and litter.

The climb began with relentless rain. One team member's raincoat was packed away, requiring emergency sharing of rain gear. We walked 3.5 hours in heavy rain to Met Station, drawing parallels to special needs parenting—when do you get a break? The concern never stops, even during sleep.

Day 3 - The Vertical Bog

Cold night, fitful sleep, and altitude effects began showing. After breakfast and gear checks, we started the infamous "vertical bog"seemingly endless uphill terrain through beautiful alpine forest and moorland. Rain returned as light drizzle, but sudden squalls caught some unprepared. Lunch brought arrowroots, sweet potatoes, chicken, and reminders to drink water as altitude killed appetites. The stunning scenery raised spiritual questions about creation and purpose. We crossed Teleki River, refilled water bottles, and pushed toward the notorious "200m to Makinders" sign (sometimes graffitied to read "2000m" by frustrated climbers). Reaching Makinders cabin brought relief-hot tea, popcorn, and dry clothes after another rainy day.



Interested in joining the 2026 Autism Awareness climb of Mount Kenya starting on March 29th?

Please contact admin@eaacdafrica.org

Day 4 - Summit Day

Dawn broke with frost after overnight rain. The mountain glistened white—we climbed in the snow. Altitude affected everyone: nausea, headaches, lost appetite, and insomnia. I reflected on my autistic grandson—how does he experience sound, texture, memory? The summit ascent proved gruelling. Light rain continued as we single-filed up, me setting the slow pace to help others acclimatize. Crossing scree (loose rock) covered in snow created muddy conditions. When the guide said we were only one-third up the Austrian hut, discouragement set in. The final steep section required ropes and strategic guide positioning—falls could be fatal. Steel steps marked the last stretch. Finally, all team members reached the summit! We celebrated briefly, taking photos and videos, shouting our message: "Those on the spectrum are important!" Descent proved treacherous on slippery terrain. Back at Makinders, exhausted but jubilant, we played competitive UNO games while I pondered whether my grandson could enjoy such social activities given his sensory sensitivities.

A medical emergency struck another team—pulmonary oedema requiring immediate evacuation. This reminded me: like mountain sickness, autism needs early diagnosis and intervention. Denial leads to tragedy.



Day 6 - Journey's End and New Beginning

Day 5 - Descent Begins

Despite sore muscles, spirits were high during the relatively easy descent. We saw waterbuck, buffalo, and rock hyrax, with leopard and buffalo droppings marking animal presence. Mountain weather remained unpredictable—like caring for special needs children, you expect the unexpected. More card games filled afternoon hours at Met Station, teaching lessons about playing the hand you're dealt.

The final 10km walk on paved road was easier but harder on joints. Five days of continuous walking provided deep reflection time—about life, purpose, family, and prayers for my grandson and other special needs children. At the gate, waterbucks grazed shyly while wardens congratulated us. The Eastern African Academy of Childhood Disability team met us, partners in improving life for special needs children regionally.

This climb was complete, but the journey continues. One mountain conquered, many more ahead. After five days without showering, we were grateful for the experience and ready for what comes next. The mission: raising awareness that children with autism and special needs matter, deserve support, and have gifts to share with the world.

In April 2025, the Eastern Africa Academy of Childhood Disability leadership team joined Prof. Bukusi's team for a tough day climb that tested their limits. Battling rain, cold, and exhaustion, they nearly lost their hope until seasoned mountaineers offered encouragement, showing the power of community support in overcoming challenges. The climb became a symbol of advocacy for children with Autism and special needs, affirming their value and highlighting that preparation alone is not enough- families like climbers need collective encouragement to persevere. The climb ended with renewed empathy and a strengthened resolve to continue the mission, recognizing that while one mountain had been conquered, many challenges remained, but the journey continued with a more profound commitment and the same spirit of support.



Chronicles of Professor Elizabeth Anne Bukusi:
MBChB, M. Med (ObGyn),
MPH, PhD, PGD (Research Ethics), MBE, a Fellow of the African Academy of Sciences (FAAS) and a Fellow of the East Central and Southern College of Obstetricians and Gynaecologists (ECSACOG). Experience in 2024 while climbing Mt. Kenya to raise awareness for Autism.

General Business

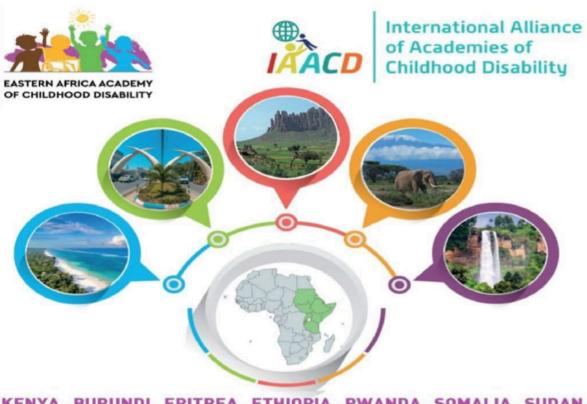
Internal Quality Improvement

The IAACD Member Organizations and Committees recently had a brainstorming session to identify needs. The needs identified included more knowledge transfer, more communication, the incorporation of people with lived experience, and raising awareness of IAACD. To foster more communication and progress, we have our first joint IAACD and Member Organization leadership meeting in November 2025. More to come on these developments!

New WhatsApp IAACD Channel is LIVE

In an effort to better reach our member organizations and beyond, we have launched a WhatsApp IAACD Channel:

https://whatsapp.com/channel/0029VbBjMj97oQhUDpsgev2i



KENYA. BURUNDI. ERITREA. ETHIOPIA. RWANDA. SOMALIA. SUDAN. TANZANIA. SOUTH SUDAN. UGANDA. DJIBOUTI

EAACD-IAACD CONFERENCE SUMMER 2028

info@eaacdafrica.org

Ubuntu - I am because WE areHumanity Towards Others

Committee Updates

- Global Professional Education:
 - Annual Listening and Sharing sessions planned for November 7, 2025 on "Moving to adulthood: Finding and navigating support pathways."
- Academy Membership Advisory: They are seeking at least one additional member organization this year and are actively looking at regions in needs of representation.
- Finance: Developing a scholarship plan for the 2028 triennial meeting.
- Communications:
 - We will be transitioning from X to BlueSky. Please follow us at @iaacd.bsky.social
 - Please follow us on the new WhatsApp IAACD Channel: https://whatsapp.com/ channel/0029VbBjMj97oQhUDpsgev2i
- Conference Planning: The 2028 triennial meeting will be hosted by the EAACD in Mombasa, Kenya!
 - Specific tracks
 - Early intervention
 - Assistive technology
 - Rehabilitation
 - Inclusive education
 - Family-centered care
 - Policy development
- Highlights
 - Simulated real-world interventions with virtual reality and AI-driven scenarios
 - Role-play workshops for inclusive education, familycentered care, and rehabilitation techniques
- Modern Plenaries
 - TED-style lightning talks
 - Ask Me Anything sessions



TIMETABLE OUT NOW-COME JOIN OUR GLOBAL COMMUNITY https://iaacd.net/khhome/listening-andsharing-sessions/



Travel the globe with us for 24 hours of virtual Listening and Sharing sessions

See past sessions https://iaacd.net/kh-home/listening-and-sharing-sessions/



The Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) is excited to announce its new name: The Oceania Academy of Cerebral Palsy and Childhood-onset Disability (Oceania Academy).

Why the change?

 Our new name better represents the geographical region we represent, and a lifelong approach to care for childhood-onset disabilities.

Why "Oceania"?

- Reflects our commitment to all of Oceania not just Australia and New Zealand, but also to Pacific Island nations and Papua New Guinea.
- Emphasises connection and collaboration across the region.

Why "Childhood-onset Disability"?

- Signals support for people with disabilities that begin in childhood and continue throughout their life.
- · Broadens our mission beyond cerebral palsy alone.

Our ongoing vision

- Foster research, education, and best practice for cerebral palsy and childhood-onset disabilities.
- Support professionals, families, and those with lived experience at every stage of life.
- Promote inclusion and equality throughout the region.

What's next?

Join us March 4th-7th 2026 for our Academy's 13th biennial conference: "Transforming Care Across Oceans", a conference that will fully embrace the spirit of the name change, with a packed programme from all over the region and intermutually.

Find out more from our conference website: OceaniaAcademy2026.com

Our name has changed, but our dedication to empowering our community across all of Oceania, for all of life – remains as strong as ever.

Email: info@OceaniaAcademy.org Website: OceaniaAcademy.org Bluesky: oceaniaacademy.bsky.social





Early Detection and Intervention in Action: A SA-ChilD and IAACD Masterclass



29 NOVEMBER 2025 08H30-13H30 (SAST)

Session 1: Early detection and intervention for CP

Welcome Address and Introductions 08h30 - 08h35

Dr Arnab Seal (IAACD) and Dr Jacqui Bezuidenhout (SA-ChilD)

Early detection and early intervention for Infants with cerebral palsy, with a focus on implementation and parental involvement.

Prof Alicia Spittle

Comfort Break 10h15 - 10h30

Session 2: Cortical Visual Impairment

Introduction

Dr Gillian Saloojee

Early and later identification of childhood-onset cerebral visual impairment (CVI): introduction to the evidence-10h35 - 11h25 based Clinical Practice Guidelines (CPG-CVI) and how they can be implemented in a multidisciplinary model

Prof Naomi Dale: Prof Els Ortibus: Prof Alison Salt

CPG-CVI Questions & Answers

Prof Naomi Dale & Prof Alison Salt

12h00 - 12h10 **Comfort Break**

CVI early detection and intervention – A mother's 12h10 - 12h30

perspective

VISIBLE intervention for seeing impaired infants with

cerebral palsy

Professor Andrea Guzzetta

Thanks, and Close of Session

Dr Arnab Seal and Dr Jacqui Bezuidenhout

Registration Link: https://sa-child.org/sa-child-and-laacd-masterclass/

10h30

08h35 - 10h15

11h25 to 12h00

12h30 - 13h30

13h30 - 13h35