

SUB-SAHARAN AFRICAN CONGENITAL ANOMALIES NETWORK



**IN-PERSON GENERAL MEETING
5th NOVEMBER 2025, 11H00-13H00
MAGALIESBERG, SOUTH AFRICA**

Agenda

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1. The third sSCAN General Assembly, Magaliesburg, South Africa

The third sSCAN General Assembly was held on 5th November 2025 at the Mount Grace Hotel and Spa, Magaliesburg, South Africa. The meeting was held on the last day of the 51st International Clearinghouse for Birth Defects Surveillance Research (ICBDSR) hosted by sSCAN and Northwest University at the Mount Grace Hotel. This was the first time that the ICBDSR meeting has been held in Africa.

The ICBDSR approached the sSCAN in 2023/2024 to broaden its scope and include African partners. Drs Kalk (University of Cape Town, South Africa) and Malherbe (Northwest University, South Africa) are affiliate members of the ICBDSR and have presented abstracts at previous meetings of the Clearinghouse. They formed the local organizing committee of the 51st ICBDSR meeting co-hosted by sSCAN (Dr Kalk) and Northwest University (Dr Malherbe).

Additional funding to support the attendance of delegates from sub-Saharan Africa was secured from the South African Medical Research Council. In addition, local funding for the event was secured from the South Africa National Convention Bureau. The ICBDSR supported the conference venue and travel for the ICBDSR Executive Committee, Keynote speakers and prize winners. Otherwise, attendance was self-sponsored. Attendance was affected by the withdrawal of US federal funding support to congenital anomaly surveillance programmes.

The 3rd sSCAN General Assembly was attended by 22 participants either from or based in sub-Saharan Africa. This included new colleagues who were attending the ICBDSR meeting (Appendix 1.)

Once again, the formal programme of the ICBDSR meeting was preceded by a half-day workshop on *Birth Defects Surveillance and Research Data* hosted by Dr Boris Groisman on behalf of the ICBDSR. Thirty-three people attended the interactive workshop.

2. Review of Activities

Dr Kalk presented a review of sSCAN activities since the last meeting in 2023 (Appendix 2).

2.1 Conference presentations

Table 1. 50th ICBDSR meeting, 1 – 4 September 2024, Prague, Czech Republic

Name	Organization/country	Title
Joyce Namale-Matovu	MU-JU, Uganda	Perceptions, experiences and meanings attached to external visible birth defects by parents of children with birth defects, healthcare workers and community health extension workers in Uganda.
Helen Malherbe	RareDiseases South Africa	An audit of capacity in community genetic servicers in South Africa: a sector in crisis
George Bello	MoH, Malawi	Prevalence of adverse birth outcomes and external birth defects among women living with HIV in Malawi
Emma Kalk	University of Cape Town	The sub-Saharan African Congenital Anomalies Network

Drs Kalk and Malherbe chaired the local Organizing Committee of the 51st ICBDSR Annual meeting.

2.2 Website and Webinars

Support for the sSCAN website from the BMGF via Ubomi Buhle ended on 30 April 2025. The Global Health Network (TGHN) which hosts the website agreed to continue this role gratis until 31 December 2025. Thereafter the site will be suspended until further funding is available. No data will be lost, however (website >£6,211 per year).

Since 2021, sSCAN has hosted 15 webinars moderated by TGHN and presented by regional and global experts sharing data and best practice on topics relevant to congenital anomalies in sub-Saharan Africa. The recordings are available as free resources on the sSCAN website (Table 2.)

The webinars were organized by members of the Steering Committee. There has been an increase in registrations and actual attendance over time (Table 2.) with a global spread (Figure 1.)

Figure 1. Sample Reach of sSCAN Webinar Registration (courtesy The Global Health Network)

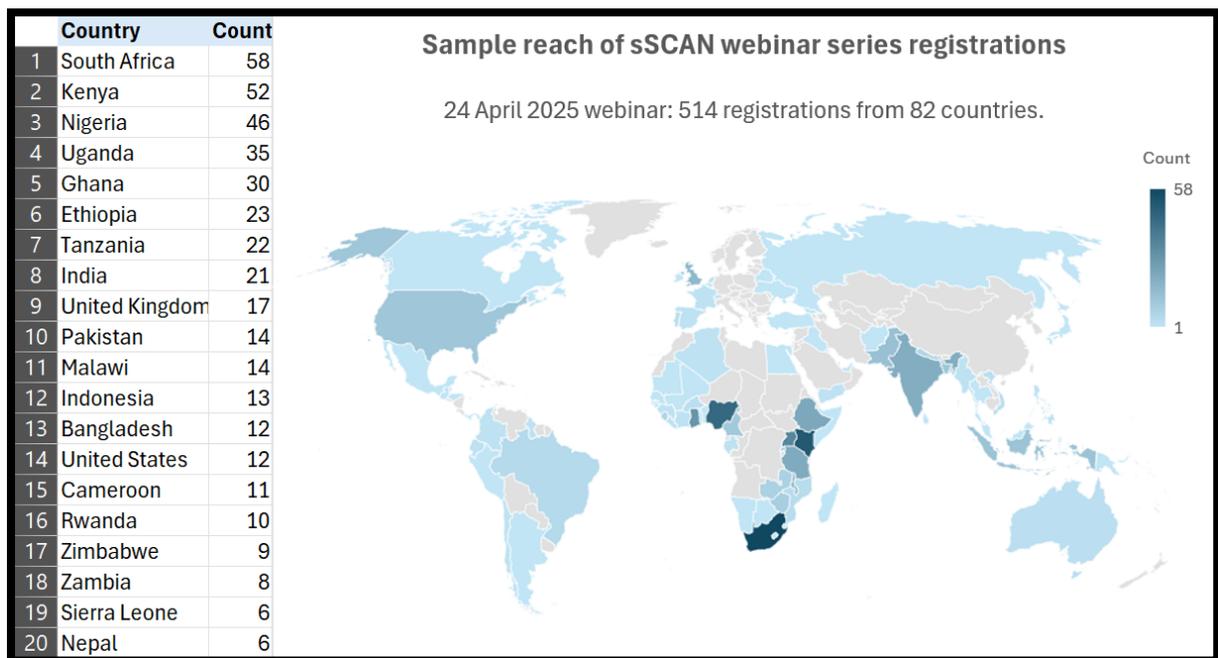


Table 2. sSCAN Webinar Series

Title	Date	Registered	Attended
sSCAN: Birth Defects Surveillance: why and how, the African Experience Part 1	30 June 2021	96	67
Addressing Congenital Anomalies and Triple Surveillance on the Path to meet SDG3 Targets	28 July 2021	73	34
sSCAN: Birth Defects Surveillance: why and how, the African Experience Part 2	25 August 2021	72	37
The use of New Technologies for congenital anomaly surveillance, diagnosis and care	29 September 2021	55	27
Specialist service provision: paediatric surgery	27 October 2021	113	34
Teratogens and Pharmacovigilance	24 November 2021	204	53
Neural Tube Defects in sub-Saharan Africa	12 October 2022	175	98
Community Screening Strategies to Improve Equitable Access in Diagnosis and Management of Birth Defects: Lessons from Low and Middle-Income Countries	11 May 2023	60	24
Congenital Heart Defects in Sub-Saharan African Countries	17 July 2023	111	63
Advocacy for congenital disorders and rare diseases in sub-Saharan Africa: an expert discussion	31 August 2023	44	34
Childhood Disability in sub-Saharan Africa	02 November 2023	368	129
Orofacial Clefts in sub-Saharan Africa: Epidemiology, Care and Prevention	30 May 2024	483	150
Congenital Infections associated with Congenital Anomalies in sub-Saharan Africa	25 July 2024	298	128
Overcoming Barriers to Birth Defect Diagnosis and Management in sub-Saharan Africa	28 November 2024	331	161
Universal newborn screening in low- and middle-income countries	24 April 2025	500	200

sSCAN no longer has central funding to support webinars and we encourage members to include this in grant applications. (cost >£2,422 per webinar).

2.3 Publications

The Steering Committee has submitted a description of sSCAN to the *Maternal and Child Health Journal* (selected owing to an APC waiver with UCT): Opportunities and Challenges for Surveillance of Congenital Anomalies in Sub-Saharan Africa. It remains under review.

sSCAN members have authored numerous manuscripts, a selection of which are presented in Appendix 2.

3. Funding support

A history of sSCAN funding is presented below.

1. UK MRC seed funding (2020) (Dr Barlow-Mosha, MU-JU, Uganda): set-up, administration, website, webinars, 1st General Assembly, Kampala, Uganda
2. BMGF via Ubomi Buhle (Drs Mehta and Fairlie, UCT and Wits, RSA): website, webinars, 2nd General Assembly (2023), Cape Town, South Africa
3. Support for Dr Leke's (Cameroon) successful DS-I Africa (NIH) U01 application: *AI-Assisted Echocardiography for Neonatal CHD Screening in Sub-Saharan Africa*
4. The Global Health Network: support for the website May – December 2025
5. SAMRC travel grant (Dr Kalk, UCT, South Africa): support African delegates to attend the 51st ICBDSR meeting and 3rd General Assembly (2025), Magaliesburg, South Africa

Other applications since 2023 (unsuccessful):

SAMRC-UKRI (Dr Kalk): *Childhood disability associated with congenital anomalies in sub-Saharan Africa*

UKRI Development Pathway (Dr Dolk): *An integrated digital health intervention to improve birth defect diagnosis and referral in low-resource areas of Sub-Saharan Africa*

The withdrawal of US federal funding has profoundly affected many of the US CDC-supported congenital anomalies surveillance projects which are affiliated with sSCAN, some of which will close completely. In the current funding climate, support for surveillance programmes is difficult to secure. This was the subject of much discussion at the 3rd General Assembly.

Suggestions included:

1. Inclusion of support of the sSCAN website and webinars in the budget of relevant grant applications. The webinars can serve as vehicles for stakeholder engagement and dissemination.
2. Seek an alternative webinar platform that may be less expensive than TGHN. e.g., submit sSCAN webinars to the SA NoDH, London School of Hygiene and Tropical Medicine series.
3. Approach family organizations for funding (website, webinars)

4. Leadership

Dr Kalk assumed the Directorship from Dr Barlow-Mosha in 2022.

Steering Group members following the 2023 General Assembly include: Helen Malherbe (NWU, SA); Aminkeng Leke (HRF, Cameroon); Modiegi Diseko (BHAP, Botswana); Samrawit Abedew (HHR, Ethiopia); Audrey Chepkemai (Moi Hosp, Kenya); Caroline Osoro (KEMRI, Kenya); Lesego Gaotshetse (UCT, SA); Ushma Mehta (UCT, SA); Robert Serunjogi (MU-JU, Uganda); Helen Dolk (UU, UK); Phylis Kisa (MU, Uganda); Eric Katagirya (MU, Uganda); Daniel Mwanja-Mumpe (MU-JU, Uganda); Hamisi Shabani (MOI, Tanzania)

Some members are not active, and meeting attendance is limited to a few. Meetings are quarterly set in advance at the beginning of the year and as required between these times. Activities have included organizing webinars, publications, funding applications and conferences.

From the 2025 meeting, Dorothy Sefara (Wits, SA), Kennedy Wekesa (KEMRI, UK) and Vuyiswa Lebeso (NDoH, SA) have expressed interest in joining.

Dr Kalk cannot remain in the Director position indefinitely, the governance documents stipulate 5 years, and a new Director needs to be appointed in 2026.

5. Discussion

5.1 Webinars

Discussion on webinars on other platforms noted above.

It is important that sSCAN maintain at least an electronic presence and payment for the website should be prioritized.

5.2 Collaborations with Ministries of Health

In order to ensure local impact in terms of CA surveillance and treatment, sSCAN should engage with Ministries of Health at all levels to maintain CA on the national health agendas.

The WHO has moved CA into the domain of Maternal and Child Health which is an opportunity to advocate for the same approach within national departments of health.

Vuyiswa performs this role in SA; Robert (Uganda) and Lola (Ethiopia) will use opportunities.

5.3 Social Media

There is a suggestion for a sSCAN social media portfolio within the Steering Committee – LinkedIn, Bluesky, X (?). These feeds can be automatically linked to the website. We need a # that can be linked with sSCAN. This led to a discussion on appropriate terminology: options included #congenitaldisorders #borndifferent #bornunique

What do parents and healthcare professionals prefer? We could conduct an informal survey via the sSCAN mailing list. It may require a focus group review of language. Terminology may need to be country-specific.

5.4 Projects for 2026

sSCAN descriptor manuscript

Social media presence

New Steering Committee membership and Director

CA atlas with African images – delegates reported experiences that parents and health workers doubted the presence of CA in African babies as all the images are of white infants so there is a need for a more representative atlas (c.f. the atlas of dermatology images in black patients).

There is consent to use the photos from the MU-JU and CHAMPS projects. Ubomi has graphics of black infants. Could this be published by an MoH? What are the copyright implications? The atlas could be presented at MHC conferences.

Appendix 1

1. Supplementary Table 1. List of Attendees 3rd sSCAN General Assembly

Name	Affiliation
Samrawit Abedew	Haranghe (Ethiopia)
Hannah Blencowe	LSHTM (UK)
Utibe Ebong	Ulster University (Nigeria)
Graham Fieggen	UCT (RSA)
Karen Fieggen	UCT (RSA)
Azra Ghoor	Rahima Moosa Mother & Child Hospital (RSA)
Helina Heluf	LSHTM (Ethiopia)
Emma Kalk	UCT (RSA)
Di Lavies	UCT (RSA)
John Lawrenson	Red Cross Children's Hospital (RSA)
Vuyiswa Lebese	SA NdoH (RSA)
Lola Madrid	LSHTM (Ethiopia)
Ntaoleng Moreko	Wits (RSA)
Hope Mwangudzah	Bristol (Kenya)
Vumela Mzangwe	UCT (RSA)
Joyce Namale-Matovu	MU-JU (Uganda)
Fikiswa Ndzulu	UCT (RSA)
Rosina Ngunguayani	WRHI (RSA)
Dorothy Sefara	Wits VIDA (RSA)
Robert Serunjogi	MU-JU (Uganda)
Thingazwa Tom	UCT (RSA)
Kennedy Wekesa	KEMRI (Kenya)
Thandokazi Yawa	UCT (RSA)