# FIGI TOGETHER TO END FEMALE GENITAL SCHISTOSOMIASIS

# FGS INTEGRATION GROUP (FIG) 2022 & 2023 HIGHLIGHTS

The FGS Integration Group (FIG) is a global coalition galvanising collective action across sectors (including HIV, cervical cancer, sexual and reproductive health and rights, and neglected tropical diseases) to address FGS through integration. This will contribute to strengthening health systems by improving the delivery of equitable and holistic health services for all people, improving women's health outcomes, and ultimately contributing to social and economic equity.

We are excited to share with you some of the key FIG moments from across the FIG partnership in 2022 and 2023.

To find out more about the <u>FGS Integration Group</u>, become a member and find out more about Genital Schistosomiasis at the <u>Global Schistosomiasis Alliance</u> webpage.

#### **FIG Partners:**





















### FIG ADVOCACY

FIG is coordinating cross-sector advocacy to increase the recognition and inclusion of FGS within women's health and rights initiatives with donors, policy- and decision-makers, programmers, technical experts and affected communities.

#### 2023

#### WHO NTD Progress Report (January 2023)

FIG was featured in the <u>WHO Global report on neglected tropical diseases 2023</u> and was acknowledged as a contribution to progress being made on Schistosomiasis elimination.

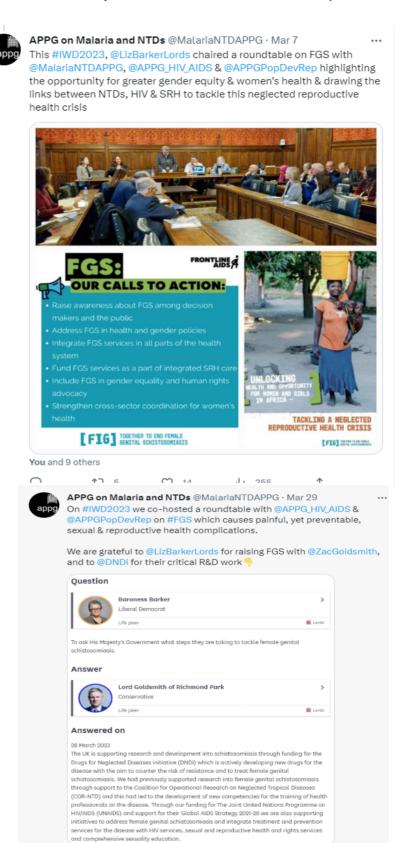


#### International Women's Day (UK Parliamentary Roundtable on FGS, March 2023)

FIG members. Unlimit Health and Frontline AIDS, coordinated a cross-party parliamentary roundtable on FGS integration with the APPG on Malaria and NTDs. APPG on HIV/AIDS, and APPG on Population, Development and Reproductive Health. The event commemorated International Women's Day by raising awareness of FGS within UK Parliamentarian interest groups on health.

In addition to the briefing, FIG launched its policy paper Unlocking Health and Opportunity for Women and Girls in Africa - Tackling a Neglected Reproductive Health Crisis.

As a result of the cross-APPG Parliamentary Roundtable, <u>Baroness Barker</u> posed a <u>Parliamentary Question</u> on FGS.



You and 8 others

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1,308

# International Development Committee's inquiry on UK Aid's impact on Sexual and Reproductive Health and Rights (UK Parliament, April and July 2023)

In April 2023, Unlimit Health and Frontline AIDS on behalf of FIG, submitted <u>evidence on FGS</u> for the UK <u>International Development Committee's</u> (IDC) inquiry on the Foreign, Commonwealth and Department Office (FCDO) approach to <u>the SRHR of women and girls in lower-income</u> countries.

Amplifying FCDO's impact on sexual and reproductive health and rights of women and girls in lower-income countries – the case for female genital schistosomiasis (FGS) integration as a multiplier for health and equity outcomes

#### FGS Integration Group (FIG)

The Female Genital Schistosomiasis (FGS) Integration Group (FIG), FIG, is pleased to submit evidence to the International Development Committee's inquiry into the effectiveness of the Foreign, Commonwealth and Development Office's (FCDO) work on sexual and reproductive health programmes in lower-income countries. FIG is a global coalition galvanizing collective action across HIV, cervical cancer, SRH and neglected tropical diseases (NTDs) sectors to address FGS through integration and strengthening health systems for women's health.

For this inquiry we are presenting evidence to make the case for the UK to provide more support to integrated person-centred approaches as a way to increase effectiveness of work to address the '3 Es' and as a multiplier for health and equity outcomes for women and girls in lower-income countries.

FIG was then invited to give oral evidence, and Dr Camilla Ducker <u>gave evidence on behalf of FIG</u> and a written response to questions from parliamentarians about the impact of FGS and its need for integration into SRHR was submitted to the IDC. You can watch the recording of the oral evidence on <u>UK Parliament TV here</u>. More recently the IDC committee asked the International Development Minister Andrew Mitchell on how FCDO will address the need to integrate FGS into SRH services:

https://twitter.com/MalariaNTDAPPG/status/1701950781455253744



## **INCREASING VISIBILITY AND AWARENESS**

#### 2022

In 2022, FIG focused on increasing awareness of FGS as a sexual and reproductive health condition and increasing the visibility of FIG in global health spaces. This included launching FIG in the UK Parliament, at the Kigali Summit and at the International AIDS Conference.





Malaria & Neglected Tropical Diseases



House of Lords reception on NTDs hosted by the All-Party Parliamentary Group on Malaria and NTDs and the UK Coalition against NTDs (UK, June 2022)

The event took place in the lead up to the CHOGM (Commonwealth Heads of Government Meeting) and the Kigali Summit on Malaria and NTDs, where governments and civil society made commitments to eliminating NTDs. <u>Baroness Liz Sugg</u> launched FIG in the UK, alongside <u>Delphine Pedeboy</u>, who spoke about her experience of FGS and <u>Felicia Wong</u>, FIG Coordination Team.



You can read more about the event in the APPG Malaria and NTDs <u>2022 Annual Report</u>. The event also drew online media attention for FGS including a feature story in The Telegraph online edition.

- Harriet Barber. The Telegraph. <u>Waterborne parasites are laying eggs inside women's</u> bodies with deadly consequences.
- The Royal Society of Tropical Medicine and Hygiene. <u>Lord Trees and Baroness Sugg</u> call to end Neglected Tropical Diseases with UK Coalition at Westminster event
- eyenews. Lord Trees and Baroness Sugg call to end Neglected Tropical Diseases with charity coalition at Westminster event



#### Kigali Summit on Malaria and NTDs (Rwanda, June 2022)

The Kigali Summit gathered the Heads of Government across NTD and malaria endemic countries. The event launched the next wave of commitment focused on progress in the next 10 years providing the perfect opportunity to secure political support and investment in

integrating NTDs programmes and highlighting the unique needs of FGS within the health system. FIG's work perfectly highlighted one of the meeting's themes on the importance of integration and cross sector collaboration to end NTDs and malaria. Julie Jacobson (Bridges to Development, FIG Coordination Team) launched FIG on stage amidst heads of state, ministers of health and CEOs.





#### The 24th International AIDS Conference

Montreal, Canada, and virtually

#### The 24th International AIDS Conference (Montreal, 29 July- 2 August 2022)

Frontline AIDS, Avert and LVCT Health represented FIG at the conference. Almost 13,000 HIV professionals and members of civil society, including approximately 3,600 virtual delegates, took part in AIDS 2022. This was the first in-person International AIDS Conference that had taken place since the COVID pandemic. FIG was introduced and FGS awareness was raised across formal and informal conference platforms.

Bridges to Development and Frontline AIDS' abstract was accepted as a <u>Poster Presentation</u> (scroll to bottom to download): *Integration of female genital schistosomiasis into HIV/sexual and reproductive health and rights and neglected tropical diseases programs and services: a scoping review with a systematic search.* 



Frontline AIDS and the Canadian Network for NTDs hosted an informal donor dinner to raise awareness of FGS and how FGS integration is an opportunity for joined-up funding across private-public donors as well as within donors' own funding portfolios. Participants included Gilead Sciences, Children's Investment Fund Foundation, Go Further (PEPFAR), the Global Fund to fight AIDS, Malaria and Tuberculosis, the National AIDS Commission of Kenya, ViiV Healthcare, Elton John AIDS Foundation, amongst others.

An awareness raising session was held in the Global Village Women's Networking Zone called "What does Bilharzia have to do with HIV?" The session was also live streamed on the <u>#BeTeamWomen</u> facebook page. The session raised awareness amongst women's rights and women living with HIV networks within the community space in the conference. For many participants this was the first time they heard of FGS and were shocked that they had never heard about it, especially because it increases risk for HIV and cervical cancer which also disproportionately affect women across Africa.

Speakers included Dr Marc Steben (HPV Global Action, Canada), Karen Webb (Organization for Public Health Interventions and Development - OPHID) and Dr. Ntombi Muchuchuti (AIDS and Rights Alliance for southern Africa - ARASA).



On the last day of the conference, FIG had its official <u>Satellite Session</u> (scroll to bottom to view) *Strengthening health systems for holistic HIV prevention, cervical cancer and female genital schistosomiasis prevention and control services.* The session was dedicated to Dr Mwelecele Ntuli Malecela, Director of WHO's Department of Control of Neglected Tropical Diseases, who was an advocate and champion for gender responsive NTD programmes and FGS. Marike Wijnroks, the Chief of Staff at the Global Fund to fight AIDS, TB and Malaria, made opening remarks for the session, showing support of the practicality of FGS integration, 'For me, Female Genital Schistosomiasis is the next frontier, and there is such an obvious case to be made. It is logical.'







Speakers included Patriciah Jeckonia (LVCT Health, Kenya), Marijke Wijnroks (the Global Fund), Helena Nangombe (Young Women Empowerment Network, Namibia), Pamela Sabina Mbabazi (WHO, Control of NTDs), Jutta Reinhard-Rupp (Global Health Institute, Merck), Naisiadet Mason (Guttmacher Institute), Margaret Gyapong (University of Health and Allied Sciences, Ghana)



A global forum for nongovernmental organizations working together on NTDs

#### NTD NGO Network Meeting (Nepal, September 2022)

The Global Schistosomiasis Alliance, LVCT Health, Sightsavers and the Arise Consortium hosted a hybrid workshop on Cross-cutting approaches to mainstreaming NTDs: innovations, opportunities and limitations which focused on the WHO pillar: Intensifying Cross-Cutting Approaches to NTD control. The Key themes included integration, mainstreaming and coordination. Dr Victoria Gamba and Dr Akinola Oluwole led the section of our workshop on integrating Female Genital schistosomiasis into healthcare services. Dr Gamba presented on a pilot project in Kenya to integrate FGS into existing cervical cancer screening and SRH services in Homa Bay and Kwale County. Dr Oluwole reported on the COUNTDOWN project in Nigeria and Liberia, integrating FGS awareness and training for health workers, with outputs of two manuals, one for Nigeria and the other for Liberia. Breakout groups discussed key integration enablers and challenges. We saw a clear interest from NTD stakeholders and participants in working with SRH and primary health professionals to integrate FGS into health services.

- NNN 2022 FGS workshop report and slides: <u>Cross-cutting approaches to</u> mainstreaming NTDs: innovations, opportunities and limitations
- Crown Agents Article <u>NNN Conference acknowledges growing health crisis of FGS in</u> sub-Saharan Africa
- Full NNN Conference Report NTDs in health systems innovate, integrate, & empower





American Society for Tropical Medicine and Hygiene Session (Seattle, October 2022)

At the American Society of Tropical Medicine and Hygiene (ASTMH) annual meeting in 2022 in Seattle, FIG members organized a Symposium: **Breaking the silos between Tropical Medicine and Sexual and Reproductive Health**: a path towards equity, integration and sustainability.

Session recordings can be accessed here

There were also 3 proudly presented posters on the FAST Package findings and lessons learned:

- Knowledge and awareness of schistosomiasis and female genital schistosomiasis among teachers in Ghana by Margaret Gyapong et al.
- Understanding the socio-cultural determinants of health-seeking behaviours and health information trust among women at-risk for female genital schistosomiasis in Ghana: A mixed-method study by Kruti Patel et al.
- Community awareness and knowledge on Schistosomiasis and Female Genital Schistosomiasis (a neglected sexual and reproductive health issue): Findings from the FAST Package baseline assessment in Ghana and Madagascar by Alison Krentel et al.





#### International Conference on Family Planning (Thailand, November 2022)

Frontline AIDS and LVCT Health ran a lunchtime roundtable discussion on FGS and SRHR/Family Planning and a side event on innovations in HIV prevention which included FGS and an introduction to FIG; Frontline AIDS and LVCT Health also held an <u>introductory</u> webinar for Frontline AIDS partners on FGS/HIV integration in the lead-up to the conference.





#### Women Deliver Conference (Kigali, 17-20 July 2023)

Held every three years, Women Deliver is the largest multi-sectoral convenings to advance gender equality. FIG members were delighted to attend, joining colleagues to urge the integration of FGS services into SRHR and primary care. Events included:

- The screening of <u>Female genital schistosomiasis</u>: <u>Ending the neglect</u>, a short film by Frontline AIDS and LVCT Health at Women Deliver Arts & Film Festival
- A Q&A and direct partner outreach session on FGS by <u>Bridges to Development</u>, Frontline AIDS, LVCT Health and Sightsavers
- 'Achieving Gender Equality in Burkina Faso: Spotlight on challenging issues', a side event held by Uniting to Combat NTDs, a FIG friend and FGS champion. The event invited renowned leaders, medical professionals, champions and activists to discuss how Burkina Faso is progressing towards gender equality.



Dr Lilian Otiso (left), Executive Director of LVCT Health, and Dr Julie Jacobson, Managing Partner and Co-Founder of Bridges to Development, joined other FIG members for a Q&A event at Women Deliver in July.



#### American Society of Tropical Medicine and Hygiene 2023 (Chicago, October 2023)

There were many presentations and posters about FGS at ASTMH this year including:

- Poster by Ruth Allotey, Navigating Barriers to Awareness Creation on Female Genital Schistosomiasis: A Case Study in the Central Region of Ghana
- Poster by Isis Umbelino-Walker, Integration of female genital schistosomiasis into HIV/sexual and reproductive health and rights and neglected tropical diseases programs and services: a scoping review with a systematic search
- Presentation by Ruth Allotey, Case Study (2) Female Genital Schistosomiasis at Symposium 2: How the pandemic pushed the paradigm to elevate the voice of health care providers in public health problem-solving
- Presentation by Martha Mberu, Expanding Female Genital Schistosomiasis (FGS)
   Learning and Application through an Online Training for Mixed Cadres of Health
   Care Workers in Francophone Africa
- Abstract by Olimpia Lamberti, Association of female urogenital schistosomiasis with high-risk human papillomavirus among women in Zambia: baseline results of a longitudinal cohort study (the Zipime Weka Schista study)
- Poster by Omosefe Osinoiki, Barriers to Female Genital Schistosomiasis care management in Nigeria; Community Members and Health Workers Perspectives
- Poster by Iris Kamilla Ottosen, Gaps in bedside protocols and policies for management of Female Genital Schistosomiasis in endemic South Africa and nonendemic Norway
- Presentation by Navneet Kaur, Nilanjan Lodh, Prevalence and distribution of Female Genital Schistosomiasis (FGS) across three endemic countries, timeline, and age groups
- Presentation by Emmanuel Donkoh, Acceptability of genital self-sampling for the diagnosis of female genital schistosomiasis in hard-to-reach communities
- And more...!

Integration of female genital schistosomiasis into HIV/sexual and reproductive health and rights and neglected tropical diseases programs and services: a scoping review with a systematic search





#### ICASA (Zimbabwe, December 2023)

FIG Partners shared social media messaging around FGS and the link to HIV and the need for comprehensive FGS integration around ICASA. LVCT Health, Avert and Frontline AIDS organised an FGS Spotlight Session and handed out leaflets generating engagement with the conference attendees.

Mrs. Privillage Charashika from OPHID had an abstract titled *Are we FGS and HIV aware? Community Health Workers' Knowledge on Female Genital Schistosomiasis (FGS) and HIV risk in Zimbabwe* accepted for presentation.



Global Schistosomiasis Alliance

## FIG PARTNERS' HIGHLIGHTS

**FGS Accelerated Scale Together (FAST) Package** (Bridges to Development, Bruyère Research Institute, Schistosomiasis Control Initiative Foundation, Merck Global Health Institute, NTD support centre, University of Health and Allied Sciences, Ghana, and WHO-ESPEN.)



The FGS Accelerated Scale Together (FAST) package is a project aimed at reducing the morbidity of FGS by building the capacity of health workers on the diagnosis, treatment, prevention, awareness creation and training of personnel to detect, treat and record FGS.

• <u>Hiding in Plain Sight</u> (FAST Package partners) article in Think Global Health by Julie Jacobson, April 2022



 Improving the Response of Health Systems to Female Genital Schistosomiasis in Endemic Countries through a Gender- Sensitive Human Rights-Based Framework in Diseases (FAST Package partners: Carol Vlassof, Kazeem Arogundade, Kruti Patel, Julie Jacobson, Margaret Gyapong and Alison Krentel)





Improving the Response of Health Systems to Female Genital Schistosomiasis in Endemic Countries through a Gender-Sensitive **Human Rights-Based Framework** 

Carol Vlassoff 1,\*, Kazeem Arogundade 1, Kruti Patel 1, Julie Jacobson 2, Margaret Gyapong 3 and Alison Krentel 1

<u>Introduction to FGS | Nursing Now Challenge</u> (FAST Package partners)



An introduction to FGS





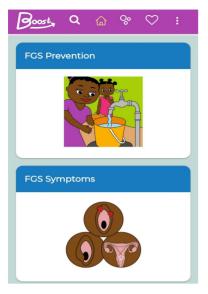




"The FAST Package: Addressing FGS in Ghana and Madagascar" (Dr., Alison Krentel, Bruyere) Global Health Learning Network Webinar Series held on the 17th of November 2022 and again in January 2023



#### **Boost job aide** (Avert)



Avert has included a new module on FGS into Boost — their job-aide for community health worker and peer educator cadres (CHWs). Boost can be shared and downloaded for free. It is also accessible offline, supporting CHWs to build their knowledge, confidence, and skills to support community health. The FGS module was co-created in partnership with OPHID and its active cadre of CHWs in Zimbabwe. Boost is available in English, Shona and Ndebele. Boost can be cobranded and further content added to meet the specific needs of organisations. Please reach out to the Boost Manager at Avert if you would like to know more: Lucy.gale@avert.org

#### Female genital schistosomiasis (FGS): Ending the neglect (Frontline AIDS and

LVCT Health) Video - Homa Bay, Kenya
Search



Female genital schistosomiasis (FGS): Ending the neglect



# Integration of FGS into Global Fund country proposals webinar (Frontline AIDS) 17 January, 2023



Integration of female genital schistosomiasis into HIV/sexual and reproductive health and rights and neglected tropical diseases programmes and services: a scoping review in Sexual and Reproductive Health Matters (Frontline AIDS and Bridges to Development) October 2023

Review Article

Integration of female genital schistosomiasis into HIV/sexual and reproductive health and rights and neglected tropical diseases programmes and services: a scoping review

Isis Umbelino-Walker ☑ ⑩, Felicia Wong, Matteo Cassolato, Anastasia Pantelias, Julie Jacobson & Christine Kalume

Article: 2262882 | Published online: 18 Oct 2023

#### **She is Seen Campaign** (Unlimit Health)

In November 2023. Unlimit Health launched a Big Give Christmas appeal. She is Seen: Support women in Côte d'Ivoire to come out of the shadows. Exceeding its target of 100K, they are delighted as the funds will towards go supporting a project that will benefit women affected by FGS in Cote d'Ivoire. Find out more here.



She is Seen: Support women in Côte d'Ivoire to come out of the shadows













#### The FGS Integration Project (Frontline AIDS, LVCT Health, Bridges to Development)

Funded by the Children's Investment Fund Foundation (CIFF) and managed by Frontline AIDS, in collaboration with LVCT Health and Bridges to Development, the project spans from March 2023 to February 2025 in 3 counties in Kenya: Homa Bay, Kwale and Kilifi. Its objective is to enhance the incorporation of FGS prevention, diagnosis, and treatment into sexual and reproductive health and rights (SRHR) initiatives, budgets, policies, and guidelines globally. The project will produce guidance and resource materials for integrating FGS into existing SRHR interventions, conduct implementation research in Kenya to assess feasibility. acceptability, and cost, and disseminate findings to stakeholders at various levels. Leveraging



**FGS** Integration Group (FIG), the project seeks to expand access to inclusive FGS and SRH services, including HIV and cervical cancer, and contribute evidence on integration feasibility. acceptability, affordability to inform policy funding and decisions at county and national levels. The first Training of Trainers (ToT) took place in Homa Bay in November 2023, and cascade training planned for early 2024, prior to data collection.

Women wash clothes and utensils at the lake in Homa Bay, Kenya. Female Genital Schistosomiasis (FGS) is endemic in the region due to the presence of waterborne snails which carry the parasite that causes FGS. @Frontline AIDS/Denis Mwangi/2023