

# A Call to Action: Ending the Neglect of Female Genital Schistosomiasis



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January 30, 2021, marks the second annual World Neglected Tropical Disease Day (World NTD Day). In Canada, various events will highlight the importance of neglected tropical diseases and signal ways in which Canadian clinicians, researchers, advocates, students, and their development partners can address neglected tropical diseases and contribute to global goals of control, elimination, and eradication.

Neglected tropical diseases are a group of 20 communicable diseases found predominantly in subtropical and tropical regions. Over one billion people currently live in areas endemic for one or more neglected tropical diseases. We consider these diseases *neglected* because they have not received the attention and funding they warrant given the significant number of people at risk of infection or living with infection-related chronic conditions. These often disabling conditions cause stigma, reduce economic opportunities, and contribute to poor mental health outcomes for affected individuals and their families. Female genital schistosomiasis (FGS) is among the most neglected of these conditions.

Called “the sexual and reproductive health issue you’ve probably never heard of,”<sup>1</sup> and the “secret scourge of girls and women,”<sup>2</sup> FGS is one of the common conditions facing many sub-Saharan African communities. FGS is caused by infection with *Schistosoma haematobium*. Infection occurs through contact with contaminated freshwater, making poor water and sanitation major risk factors for FGS. Women and children are particularly at risk for infection as they bathe, collect water, and carry out household tasks in and near water. Worldwide, an estimated 112 million people are believed to be infected with *S. haematobium*. Around 90% of people requiring treatment for schistosomiasis live in Africa,<sup>3</sup> and many face re-infection even after treatment with praziquantel.

Women with FGS may experience signs and symptoms similar to those of sexually transmitted infections, including a burning sensation in the genital area, spot bleeding, abnormal smelling discharge, lower abdominal pain, hematuria, and genital ulcers.<sup>4</sup> Long-term complications of FGS include damage to reproductive organs, infertility, ectopic pregnancy, spontaneous abortion, low birth weight, and preterm birth.<sup>5</sup> Urogenital schistosomiasis can go on to cause fibrosis of the bladder and ureter and kidney damage, and it is a risk factor for bladder cancer. Increasingly, evidence demonstrates that FGS is a potential risk factor for HIV infection.<sup>5</sup>

An estimated 40 million women and girls in sub-Saharan Africa live with FGS,<sup>2</sup> many of whom do not receive the correct diagnosis owing to poor health care worker knowledge about the condition or limited access to health care services.<sup>6</sup> Diagnosis is more accurate with the use of a colposcope to identify the sandy lesions and typical vascular patterns that characterize the infection (see the FGS Pocket Atlas <https://apps.who.int/iris/handle/10665/180863>) and histopathology of the biopsied lesions, which will not be available in many low-resource health facilities.<sup>5</sup> Women who have incorrect or missed diagnoses must face the ongoing physical and mental health consequences of FGS, which are often associated with stigma, untreated infertility, and suspected STI infection.<sup>6</sup>

Many of the women and girls who are at high risk of FGS are also at risk for infection with human immunodeficiency

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virus (HIV) and human papillomavirus (HPV). While this “triple burden” represents a serious threat to the reproductive and sexual health of women and girls, it also presents opportunities for programmatic integration and efficiencies with respect to prevention and diagnosis.<sup>5</sup> Recent calls for integration of FGS into the global HIV/AIDS agenda and the global call for cervical cancer elimination offer the policy frameworks to realize this objective. Programmatic integration strengthens all levels of the health system, from the training of medical personnel through to the diagnostic and preventive services offered at the health facility level. As Engels and colleagues state, there is increasing evidence that “controlling one of these diseases may decrease the unwanted outcomes for the two others.”<sup>5</sup>

Why does FGS matter to Canadians? The Feminist International Assistance Policy (FIAP) guides current government policy on Canadian overseas development. In the FIAP, the government signals the importance of addressing some of the most neglected areas of sexual and reproductive health. FGS represents one of these areas.

Despite the fact that millions of women and girls in sub-Saharan Africa have FGS, it remains a relatively unknown disease. It is imperative that clinicians working in sexual health, HPV and HIV clinics, and other programs in sub-Saharan Africa understand the prevalence of *S. haematobium* in the region. The World Health Organization’s Expanded Special Project for Elimination of Neglected Tropical Diseases provides up-to-date mapping information on schistosomiasis for sub-Saharan Africa (<https://espen.afro.who.int/>). It is also important for clinicians in Canada to consider the possibility of schistosomiasis and its complications, including FGS, when providing care to women and girls

coming from endemic areas. Let’s end their suffering here in Canada through good clinical care and correct diagnosis.

Finally, we cannot address FGS on its own. This January 30, let’s strive to make Canada a global leader in the movement to end FGS by ensuring that we adapt diagnostic and treatment protocols for HPV, HIV, and STIs to include FGS, to support chemoprophylaxis with praziquantel in endemic communities to reduce the incidence of FGS, and to support integrated programming to break down the inefficiencies of siloed approaches to sexual and reproductive health. Forty million women and girls in Africa are waiting.

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