

## Annual Report 2016

### Fistula Treatment Program



March 2016 Fistula Patient Group

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With additional support from:

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## **0 - Executive Summary**

The Fistula Treatment Program at CoRSU started in 2015 after a year of preparations with a first grant from Fistula Foundation. Additional support was given through MoH Uganda/UNFPA, Direct Relief and Funds for Fistula. The VVF Program has been developed by Dr Judith Stenkamp, who is CoRSU's gynaecological surgeon and VVF program coordinator, supported by a roster of visiting surgeons. In 2015 three treatment weeks were conducted and a total of 71 patients were treated. In 2016, with additional funding from Fistula Foundation, the number of patients treated was scaled up. Four treatment weeks were conducted in February, May, September and November. In total 136 patients received treatment. Of these 136 patients, 48 were patients with VVF or other causes of incontinence, 58 were patients with 3<sup>rd</sup>/4<sup>th</sup> Degree Tears and 14 were patients with genital prolapse, 16 patients did not receive surgery, either due to other conditions which needed treatment first, conservative treatment or after diagnostics revealed no indication for surgery.

## **1 - Concept of the VVF Programme**

The fistula repair programme at CoRSU makes use of the available theatre and ward (hostel) facilities as well as professional medical support staff, such as anaesthesia and nursing. A volunteer consultant gynaecologist based at CoRSU is the programme coordinator and resident fistula surgeon. She is supported by a roster of international and Ugandan visiting VVF surgeons.

The programme has begun with a scalable treatment week ("camp") approach. Patients are mobilized to present during a dedicated week for fistula surgery. Patients need post-operative care of two to three weeks and during this time stay in the hospitals hostel. CoRSU has a capacity to treat batches of ca. 25 - 30 patients at a time. The current target of the program is to conduct five to six VVF treatment weeks annually.

Key to this target is effective mobilization of patients. The program includes an element of transport cost refund, to facilitate access to the CoRSU facility. Recruitment of patients builds on two pillars:

- the CoRSU's own dedicated fistula patient mobilization outreach programme which is embedded in CoRSU's community based rehabilitation outreach at large.
- the CoRSU Hospital network of referral hospitals and clinics across the country which have been informed of the new service for fistula patients, as well as partnerships with non-governmental community based outreach programs that refer patients.

VVF repair services provided by CoRSU are thus part of a dedicated community based rehabilitation network for the mobilisation for treatment and subsequent reintegration of women with fistula.

The strategic objective of CoRSU is to develop a permanent Fistula Unit which provides continuous surgery services based on a permanent fistula surgeon position to be established. This unit is to be supported by a dedicated fistula outreach social worker team,

which will be focused on fistula patient mobilization in remote areas of Uganda. In this way CoRSU Fistula Unit will in the medium term become a dedicated fistula treatment and training facility.

## **2 - Activity Report**

### **Patient mobilization**

The mobilization is theoretically based on two pillars: referral from co-operating partners of CoRSU and active mobilization through the VVF-Programm in cooperation with CoRSU CBR Team. In practice no patients were recruited through referral, except 10 of which were mobilized by TERREWODE under a cooperation agreement to cover costs of mobilization. The majority of the 136 patients were recruited through the outreach of the VVF programme.

Under the VVF programme, mobilization is conducted by the VVF Programm Coordinator partially supported by the CoRSU social worker, whilst available. The screening activity is, at the same time, used to review already operated patients. The uptake of this opportunity is increasing as patients are instructed at discharge of the hospital.

It has to be noted that CoRSU Hospital's services are meanwhile known to the communities. Many parents are bringing their children for registration to the respective screening dates with orthopaedic and plastic conditions. Around 160 children have been seen and registered and information passed on to the CBR team.

Outreach is currently focused on the northern districts of Ngora, Kaberamaido, Dokolo, Apac and Nwoya where good relations have been established. Outreach activities are based on agreement with the District Health Officer (DHO) in the respective districts.

Mobilization of patients in the target districts was usually done by announcing the screening date at the respective screening facility one week prior to the date on the local radio station. For the districts we are working in, these are Radio Aisa FM for Ngora District, Dokolo FM for the districts of Kaberamaido and Dokolo, Apac FM and Radio Divine for Apac District and Radio Rupiny for Nwoya District.



Mobilization in Kaberamaido HC4 May 2016

Subsequently screening was done by the CoRSU VVF Surgeon at the respective screening facility, usually at a Health Centre III/IV or the District Hospital. In all districts CoRSU has a focal persons (a VHT, medical personnel) who is in charge of organizing the transport of the patients once they have been recruited for surgery. The VVF program provides transport cost refund for patients and one attendant.

The following mobilization and screening activities took place:

- 25.01.-28.01.2016 to Ngora, Kaberamaido, Dokolo and Aduku,
- 24.02.-26.02.2016 to Ngora, Aduku and Nyambeco
- 20.04.-29.4.2016 to Aduku, Apac, Ngora, Kaberamaido, Dokolo, Anaka
- 12.09.-17.09.2016 to Ngora, Kaberamaido, Dokolo, Apac, Aduku
- 02.11.-05.11.2016 to Dokolo, Kaberamaido, Amolatar
- 09.11.-13.11.2016 to Ngora, Aduku, Ibuje

### **Treatment weeks**

Four treatment weeks were conducted by a team comprised of the CoRSU resident VVF surgeon Dr Judith Stenkamp and a visiting surgeon:

- 29.02.-04.03.2016: 18 Patients. Visiting surgeon: Dr. Frank Assiimwe, Mulago Hospital
- 02.05.-06.05.2016: 51 Patients. Visiting surgeon: Dr. Andrew Browning, Selian Hospital, Arusha, Tanzania
- 19.09.-23.09.2016: 55 Patients. Visiting surgeon: Dr. Andrew Browning, Selian Hospital, Arusha, Tanzania
- 21.11.-23.11.2016. 12 Patients. Visiting surgeon: Dr. Fekade Ayenachew, Hamlin Centre, Addis Abeba, Ethiopia

### **Physiotherapy**

Postoperatively the patients are visited room by room to be instructed on pelvic floor exercise, mainly Kegels exercise. This is done on a daily base and continued until discharge. In case of more specialized need of single patients they are treated at the physio department.

### **Psycho-social counselling**

Our patients come from different places, mostly northern Uganda, and speak Ateso, Kumam, Langi, Luo and Acholi. During their stay at CoRSU Hospital they are able to share their stories and experience that they are not alone with their condition. Often they stay in touch even after they have left CoRSU.

It has now become firmly established that after the patients have recovered from surgery, we offer 1 to 2 sessions of focus group discussions. These are conducted by Vivian Olgah Kudda, the clinical psychologist of CoRSU Hospital.



Focus Group Discussion March 2016

These are the key issues that are brought forward during focus group discussions which were held:

- Challenges from inability to give birth due to hysterectomy: Patients that lost their uterus have more pronounced psychological challenges compared to their counterparts.
- Socio-economic challenges: Since most of the women are not employed and a huge percentage live as single mother or by themselves, some resort to going back to their families of origin.
- Anxiety of having sex soon after surgery: Usually after surgery, there is tremendous joy in finding out that the incontinence has resolved. However, there is the flip side of anxiety which comes with the thought of the male spouse asking for sex when the patient returns home.
- Domestic violence: Some of the women reported being battered by their spouses and although for some it was not necessarily physical, some women received verbal and emotional insults and disgrace.
- Grief: It was also evident that a few women were still grieving the loss of their children (for those who lost children while giving birth, leading to the fistula).
- Fear of contracting HIV from unfaithful spouses
- Stigma: self-stigma, but mostly from the community and families at times.
- Anxiety of getting pregnant: It was evident that the patients had difficulties negotiating safe sex and were ignorant of family planning methods. After surgery, some were anxious about having children while others did not want to get children again.
- Low self-esteem: usually as a result of stigma due to the foul urine smell. In one of the focus groups, one lady said her husband had gotten another woman and would constantly call her (patient), “a basin”.
- Alcohol abuse: This is mainly used to cope with stressful challenges that are brought about by the conditions although none of the patients proved to be dependent.

## Training

A training session on “Postoperative Care of VVF patients” was given for the nurses of CoRSU Hospital on 23.02.2016

To increase the quality and quantity of patients screening, training for VHT’s was conducted in the districts of Dokolo, Apac and Nwoya from 04.04.-07.04.2016. In total 100 VHT were trained in the verbal screening to identify Fistula patients. At each session around 30 VHT participated.

The November treatment week was designed as a coaching session to enhance surgical skills for two FIGO-VVF Programme Fellows from Uganda (Dr. Florence Nalubega, Kitovu Hospital, Masaka, Dr. Judith Stenkamp, CoRSU Hospital). The coaching was provided by Dr. Fekade Ayenachew from the Hamlin Fistula Centre, Addis Abeba and supported by the FIGO-Fistula Surgery Training Initiative.

### 3 - A patient story: Koli Santa and her husband from Dokolo District

Koli was 27 years old when she was pregnant with her 7<sup>th</sup> child. When her husband has taken her to the hospital because the delivery did not progress they were informed that the baby had already died. She received a C/S, after which she was informed that accidentally the bladder was injured. Though she was with a catheter for 3 weeks she started leaking urine after removal.



At the hospital the husband was advised to take his wife to Mbale to receive treatment. As the husband did not have the means to take her they went back home. Coming home people started laughing and talking as she was always wet. She stopped going out. The husband would have liked to do something to stop the leaking but he did not know what.

After three years they heard about the Fistula Treatment Program from the radio and came for the screening at Kaberamaido HCIV. Koli had surgery at CoRSU in November 2016, which successfully closed the fistula. Now, they are both very happy.

## 5 – Some lessons learnt

In the first year of the programme three treatment weeks were conducted with an overall number of 71 patients being provided with surgery. In the second year four treatment weeks were conducted with an overall number of 135 patients being provided with surgery.

- The lesson learned is that a high standard of surgical treatment, post-operative including physiotherapy and psycho-social care can be delivered by the CoRSU team.

The current key challenge for upscaling the program, besides finding sufficient funding to continue to be able to offer enable free treatment, is the effective mobilization of patients to enable full utilization of the treatment week's capacities.

- It has proven to be effective to work with dedicated up-country mobilization campaigns prior to camps in conjunction with the district health teams. Under this approach the social worker and fistula surgeon travelled to up-country health facilities together to screen patients at district health centres in conjunction with the respective district Village Health Teams (VHT's). Mobilization is based on prior radio announcements of the screening dates and locations.

However, the approach to work directly through VHT, based on intensive training, did not yield the expected results. The expectation that VHT will mobilize for the program when they hear the announcement on the radio did not prove correct. It was found that it will need a personal relationship with a few motivated persons (such as VHT, ex-patients, etc.), as well as some monetary facilitation to make the concept of VHTs mobilizing patients, work. When asking each patient at the screening how they have heard of the program most of them will name the radio. However, imprecise radio announcements can lead to confusion and will bring many patients with the wrong conditions.

- Radio announcements are still the main entry point for patients to learn about the program. It is essential to make the radio announcements as precise as possible.

As the Fistula Treatment Program is part of CoRSU Hospital and during trainings the other conditions (orthopaedic/plastics) treated at CoRSU are also communicated, parents come and bring their children for the screening dates. Since the only social worker doing outreach, William Baluku, left CoRSU, the work load for handling these orthopaedic/plastics patients remained with the VVF surgeon who does the screening for fistula patients. During this year at least an additional 150 children have been seen. At one occasion CBR worker Agnes Nabawanuka accompanied a screening trip which was very helpful as she could handle these patients. CoRSU needs to explore how it can establish its up-country outreach programme in a more systematic manner by combining activities of the fistula screening program and the CBR program for plastic and orthopaedic conditions.

- CoRSU needs to explore how it can establish its up-country outreach programme in a more systematic manner by combining activities of the fistula screening program and the CBR program for plastic and orthopaedic conditions. This requires the CBR Department to recruit and task a team of social workers to assist combined outreach

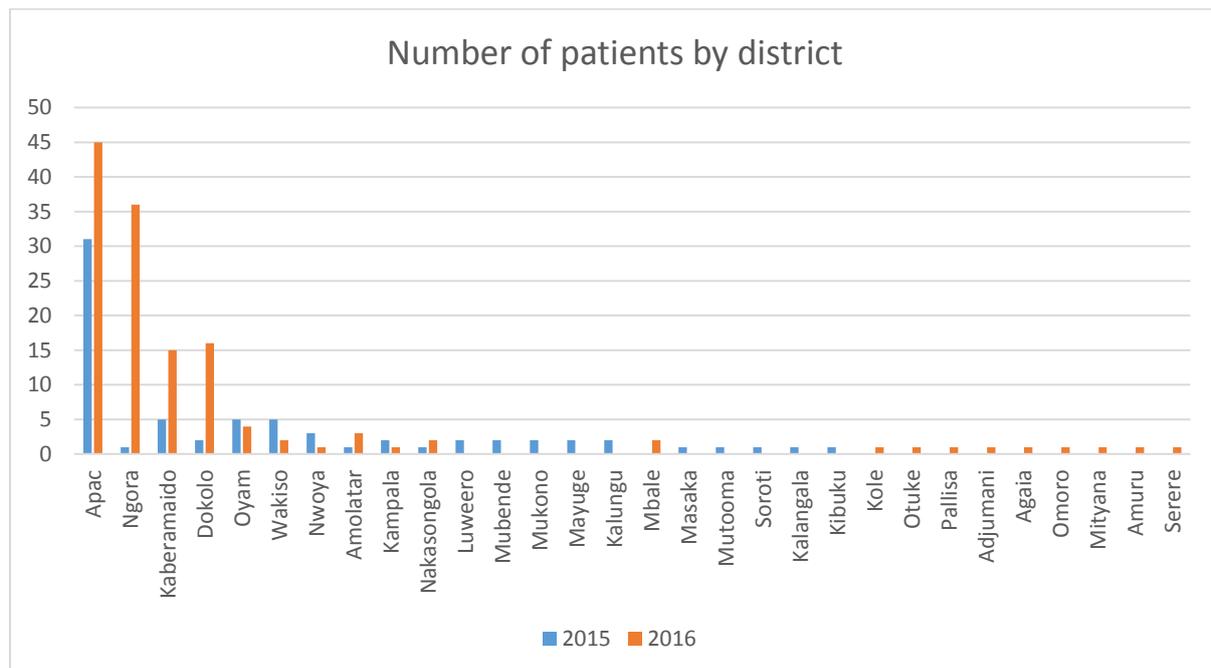
activities / screening trips for both programmes in the areas beyond the Kampala region. This will be more cost-effective for both programs.

During the outreach we have mobilized many patients with 4th Degree Tears – a condition which can be treated with lower levels of surgical skill proficiency compared to more complex VVF surgery.

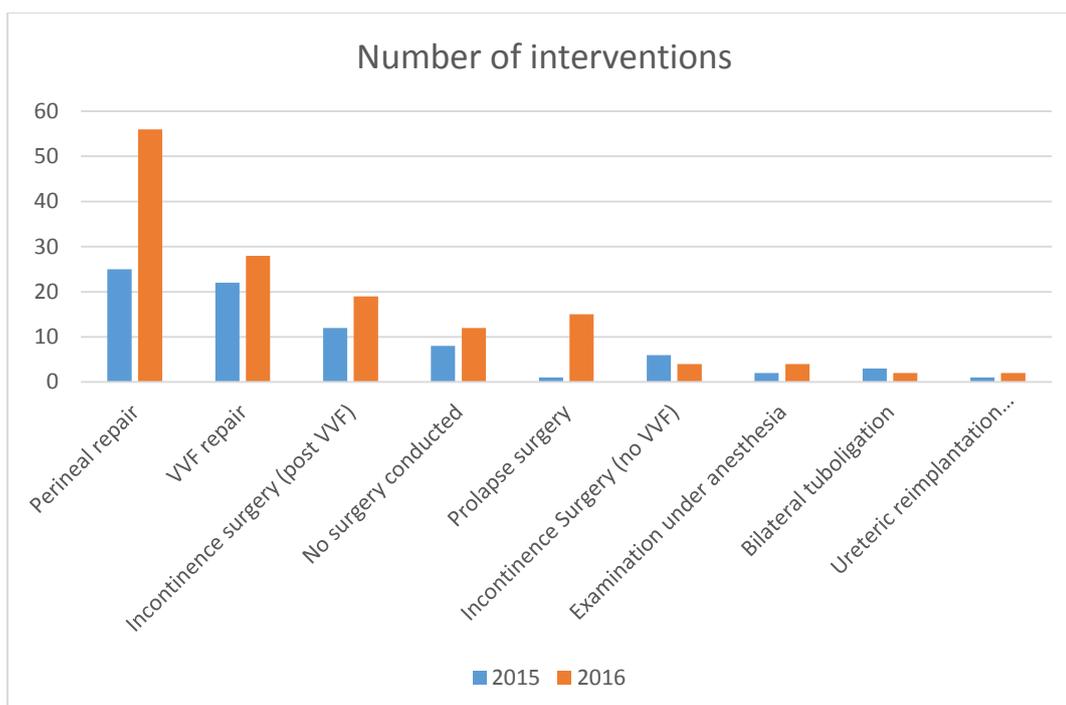
- As we have found many tears in Apac District we suggested to the partners in Aduku to conduct a training to learn the repair of 4th Degree Tears. It would be an opportunity to invite surgeons from the surrounding hospitals to learn the procedure so in future these women could be treated from their home area.
- The conditions of tears and genital prolapse do not necessarily have to be treated during VVF treatment weeks. If the hospital capacity allows, it could in future be possible to treat these patients outside of treatment weeks.

## 6 - Facts and Figures

In total we treated 136 patients in 2016, up from 71 in 2015. Our patients mostly come from the four districts we are actively mobilizing from which are Apac, Ngora, Kaberamaido and Dokolo. The districts which follow in number are the ones neighbouring these districts.



The main procedures performed are perineal repairs, which was done for 24 patients in 2015 and for 65 patients in 2016. Second are fistula repairs and followed by incontinence surgeries for post fistula repair conditions. These are flaps, slings and release of vaginal scarring to improve the urethral incompetence which often occurs after obstetric fistula. The fourth biggest group of surgeries done are genital prolapse surgery. Incontinence surgery not related to fistula but severe stress has also been performed.



The success rates are based on outcomes at the time of hospital discharge. The outcomes for tears are expected to be better, as the healing process was still ongoing at the time of the discharge.

Outcome of surgery	2015	2016
<b>VVF and other incontinence surgery</b>		
V0- no improvement	2,70%	8,06%
V1- partial improvement	18,9%	11,29%
V2- cure, no more leakage of urine	78,3%	80,6%
<b>Tears</b>		
T0- no improvement	0%	9,2%
T1- can control stool	0%	12,30%
T2- can control stool and gas	100%	78,46%

## 6 - Funding

Fistula Foundation is the main supporter of the programme and provides funds for patient treatment and mobilization. Additional support has been provided by other partners: medical consumables were provided by Direct Relief, surgical equipment, consumables and contraceptives were provided by the Uganda Ministry of Health through UNFPA Fistula Program and Uganda Health Marketing Group, Funds for Fistula eV provided outreach material and equipment. The VVF surgeons Dr Stenkamp and Dr Browning have provided their services on a voluntary basis. The International Federation of Gynaecology and Obstetrics supported a VVF surgeon training at CoRSU. Individual donations were received from Fiona Davies and Bianca de Bakker.

**Indicative overview of the sources and use of funding for the Fistula Program (in USD).**

	Fistula Foundation	Funds for Fistula	Direct Relief	Ministry of Health (UNFPA & UHMG)	International Federation of Gynaecology & Obstetrics (FIGO)	Browning *	Stenkamp*	Individual Donations **	<b>Total</b>
Surgeon	1.575	1.458			1.000	2.750	14.400		<b>21.183</b>
Medical equipment		842							<b>842</b>
Medical consumables	459		1.623	250				484	<b>2.816</b>
Mobilization	5.224	180							<b>5.404</b>
Patients: Treatment Costs	37.347							181	<b>37.528</b>
Patients: Transport Costs	7.842								<b>7.842</b>
Training	877								<b>877</b>
<b>Total</b>	<b>53.324</b>	<b>2.480</b>	<b>1.623</b>	<b>250</b>	<b>1.000</b>	<b>2.750</b>	<b>14.400</b>	<b>665</b>	<b>76.492</b>

\* Volunteer service: valued as days x average cost of specialist surgeon at CoRSU of 150 USD/day

\*\* Donations: Fiona Davis, Bianca de Backer