

Collaborative Wilms Tumour Africa Project

Dear supporters, colleagues, friends,

We hope you will enjoy reading this third newsletter of the SIOP Africa / PODC Collaborative Wilms Tumour Project.

As a team we are pleased with progress so far. We have been treating and including more patients every year, in total now almost 200 children. End of treatment outcome has increased to 15% since the implementation of the adapted treatment guideline and the start of the collaborative project. Also 'abandonment' of treatment (incomplete treatment) has reduced significantly to 10% with the provision of (part of) the treatment costs and (partial) funding of associated costs such as accommodation and travel.

Dedicated long term follow up, visiting the homes (please see below), in Malawi of children treated for Wilms tumour more than 5 years ago, helps us to know the long term survival of these patients and to assess the true impact of interventions.

Successful and constructive site visits were done in Addis Ababa, Ethiopia and Harare, Zimbabwe and we are pleased that these centres are now active partners of the collaboration. We look forward to seeing many of you all at the SIOP meeting in Dublin in October and would you like to thank you for all your support in many different ways.

With kind regards; *Trijn Israels (coordinator), Lorna Renner (Chair SIOP Africa and steering committee), Liz Molyneux and Francine Kouya (steering committee) and Liz Burns (World Child Cancer)*

<http://paedonc.wix.com/wilmsafricaproject>



Multi-disciplinary team in Mbongo Baptist Hospital, Cameroon (l-r); Joel Kaah, Dr Paul Wharin, Comfort Kimbi, Prof Peter Hesseling, Dr Francine Kouya, Philippa Nana

Patient Story

Sonia* is 5 years old and was admitted to Mbongo Baptist Hospital (MBH), in the Northwest Region of Cameroon with abdominal distention for 4 months. She consulted initially at a general hospital but her grandmother decided to bring her to MBH. Here she was diagnosed with a Wilms' tumour with metastasis to the liver. Sonia and her grandmother live in Douala about 7 hours drive from the hospital. She could not afford transportation to and from hospital for treatment so stayed in the hospital for the first 5 weeks then moved to a self-care home. From there she came in every week to complete the 8 weeks of pre-operative



*Patient names have been changed to protect their identity

chemotherapy. Through this collaborative project she was provided with treatment costs, a mattress, some food items and cooking utensils. At the end of the 8th week Sonia was re-admitted into hospital for surgery, after which she went home. Her grandmother brought Sonia every 3 weeks for her post-operative chemotherapy. They have been very dedicated and have never missed an appointment. Sonia completed treatment in July 2014 and has been followed-up every 6 months for 24 months. When she was last seen by the outreach team in June 2016, Sonia was a healthy and happy girl. *Story written by Philippa Nana*



Active Follow-up in Malawi

In May 2016 Dalida (data manager) and Mirjam (Dutch medical student) have been actively following up some of the children that have been treated for Wilms' tumour at the Queen Elizabeth Central Hospital in Blantyre between 2008 and 2010. Starting very early in the morning, they drove through the country to try to find the children in their villages. The importance of an accurate map on the patient registry form cannot be emphasised enough as it often took more than an hour to actually find patient's homes. Many of the children were living in mud-built houses in small villages, far from well-maintained roads, and some of these places were unreachable by car. All this gave a good impression of the trouble some of the families have to go through to reach a health facility. On a few occasions they found out that the child had passed away, and the exact cause was often hard to retrace. Other times they came to the house and found ill-looking children, where the parents turned out not have the money to pay for transport to get to a hospital. These families were reimbursed through the collaborative project funding and were asked to come to QECH as soon as possible, and luckily in all three occasions it turned out that it was not a relapse of the disease. Nevertheless, it illustrates clearly how transport money can still be a major barrier for families to seek help. In many of the visits however, the children were found alive and well. It is truly amazing to see children who had been so ill in the past playing with their friends and doing well in school. *Account from Dalida Nyirenda & Mirjam de Visser*



Harare, Zimbabwe

The Paediatric Oncology Unit at Parirenyatwa hospital in Harare, Zimbabwe is one of the centres that has most recently joined the efforts of the Collaborative Wilms' Tumour Africa Project. It is the only centre in the country that provides comprehensive paediatric oncology services which include chemotherapy, radiotherapy, psychosocial support and palliative care. Surgery is carried out at Harare hospital, 15km from Parirenyatwa. The surgical unit, which also has paediatric intensive care is run by paediatric surgeons. The paediatric oncology unit has 15 beds dedicated to oncology patients.



Prof Molyneux with Sister Chidziwa, Ellen, Mirjam de Visser, Lynda, Sesta and Prof Chitsike

*Patient names have been changed to protect their identity

Children under 5 have free medical treatment. All oncology patients and their care takers have free meals provided by the hospital. Investigations such as ultrasound scan, CT scan and chemo drugs are funded through a local NGO. There is a playroom where volunteers regularly come to spend time with the children.

Patients with abdominal masses suspected of Wilms' tumour are referred from peripheral hospitals to the surgeons at Harare hospital. If a Wilms' tumour is suspected they are admitted to the paediatric oncology unit at Parirenyatwa Hospital where, after imaging, are started on pre-operative chemotherapy. After the recommended pre-operative chemotherapy, the children are transferred back to Harare hospital, accompanied by the surgical forms for the surgeons. Within 24 hours of surgery, the specimen is collected by the pathologist-technician and brought back to Parirenyatwa hospital for the pathologist to report on. Although the cooperation between the hospitals provides an extra challenge for the data collection, the team is confident that they can set up an accurate data system, which will help to keep track of the children and to make sure that no children are unnecessarily lost to follow-up. Since the start of the data collection in October 2015, 32 children have been treated using this protocol. The



The multi-disciplinary team in Black Lion Hospital (l-r); Dr Haileyesus, Dr Amezene, Dr Israels (visiting), Dr Tufa, Dr Milliard, Dr Daniel

team is excited about the cooperation and hopes that through these shared efforts care for children with a Wilms' tumour can be further improved. *Written by Prof Inam Chitsike*

Addis Ababa, Ethiopia

The team in Black Lion Hospital in Addis Ababa, Ethiopia are admitting 600 patients with new malignancies each year. They are keen to participate in the Collaborative Wilms Tumour Africa Project. The team expects to restart including patients in the coming weeks. They will have weekly multi-disciplinary team meetings and will, as other centres, use the financial support to pay for treatment (especially actinomycin) and other support for the patients (nutritional support). Dr Israels visited the team in September to facilitate their participation – they had constructive and fruitful discussions. The collaborative group is looking forward to working with the Black Lion Hospital team.

Thank you to all of our supporters, including our funders the International Society of Paediatric Oncology (SIOP), World Child Cancer, VU University Medical Center and Dutch Childhood Cancer Parent's Organisation (VOKK).



VU medisch centrum



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