

Collaborative Wilms Tumour Africa Project

Welcome to the 2nd edition of this newsletter, aiming to keep all partners and supporters updated with progress in this collaboration.

Outcome – Preliminary figures

The primary aim of this project is to improve survival of children with Wilms tumour in the participating centres. We have seen in Malawi, when we introduced a similar adapted treatment guideline including social support to enable parents to complete treatment of their child that survival increased from below 25 – 30% to almost 50%. Incomplete treatment (abandonment of treatment) decreased to only 6%, a very low figure for a low income country.

In the baseline evaluation of outcome of treatment in all currently participating centres, overall survival was estimated to be 25%, with 31% of patients not completing treatment and 25% dying during treatment. Our aim is to decrease both incomplete treatment and death during treatment to below 10% and to improve survival to 50%.

Preliminary figures indicate that we are making progress – in the first 100 patients treated 14% did not complete treatment and 14% died during treatment. Still too many, but better than before.

The change can also be felt in the centres, for example in Kumasi, Ghana, where - since we started the project that includes financial support to pay for the treatment and additional (travel) costs – all patients have completed their treatment (or are still on it).

The collaborative is enabling both the improved care of individual patients and brings together like-minded paediatricians and oncologists to learn from and enthuse each other.

Dr Trijn Israels, October 2015

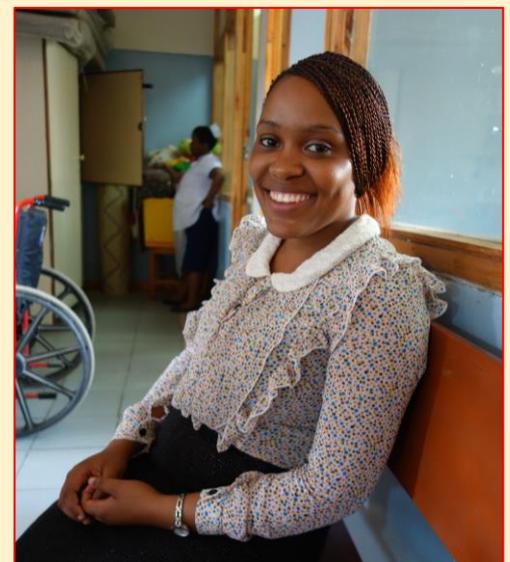
Coordinator, Collaborative Wilms Tumour Africa Project



Map showing participating centres in the collaboration

Team Spotlight – Dalida in Malawi

Dalida Nyirenda has been working with the paediatric oncology team in Blantyre for over 6 years. She combines many activities such as registering all patients, keeping track of outpatients - and follow up appointments and when necessary also doing active follow up (by phone or car). She joins the daily ward round, knows all the patients and where they are in their treatment and plays a key role in counseling the parents to complete treatment, with active follow up when needed. For the Collaborative Wilms Tumour Africa Project she completes the patient registration forms including additional details such as distance to the treatment centre and size of the tumour before and after chemotherapy. She also makes sure the surgeon and pathologist receive and complete the



Dalida Nyirenda, Malawi

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necessary forms and coordinates the transport of the surgical specimen from theatre to the pathologist.

Multi-disciplinary team in Queen Elizabeth Central Hospital, Blantyre, Malawi.

A site visit was done in Blantyre, Malawi which included a lively and interesting discussion with the paediatric surgeon, professor Eric Borgstein, pathologist Dr Steve Kamiza, Paediatric oncologist Dr George Chagaluka and data manager Dalida Nyirenda about local challenges, solutions and how to further improve care.



(L-R) Dalida Nyirenda, Dr Steve Kamiza, Prof Eric Borgstein & Dr George Chagaluka

Harare – Zimbabwe joined the collaboration

During the SIOP meeting Dr Chitsike signed the collaborative agreement on behalf of her hospital in Harare, Zimbabwe. In the last year they did a baseline evaluation of outcome of children with Wilms tumour and obtained local IRB approval. They are now a full member and are very welcome. Looking forward to a continued positive and constructive collaboration.

We also had positive discussions with representatives from Kamuzu Central Hospital in Lilongwe, Malawi where they are keen to join the collaboration.



(L-R) Prof Liz Molyneux, Prof Inam Chitsike & Dr Trijn Israels

Funding support

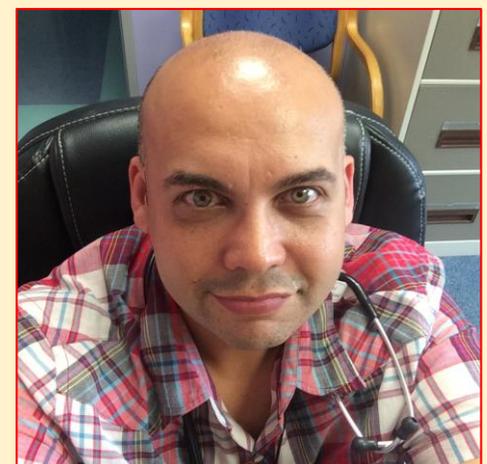
We are very grateful that both SIOP (International Society for Paediatric Oncology) and World Child Cancer are continuing their funding support to the project and we are pleased with the fruitful collaboration.



Ambassador

Every newsletter features one of the ambassadors. This time we would like to feature Marc Hendricks, who with Alan Davidson as chair and the rest of the local team and organising committee, did a great job in hosting many of us for the extremely successful SIOP Meeting in Cape Town.

“For decades children in low and middle income countries have continued to access only a fraction of the resources available for healthcare compared to their counterparts in developed countries in the face of a massive burden of disease. In a hostile environment of shrinking worldwide resources, paediatric cancer is marginalised in favour of HIV, malaria and tuberculosis. The Collaborative Wilms Tumour Africa Group is changing care for children with cancer by providing local and lasting solutions to health care problems which



Marc Hendricks, ambassador

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can radically alter children's lives. Wilm's tumour, the commonest abdominal solid organ tumour in African children accounts for a considerable burden of disease in children under 6 years of age. Collaborative work is the key to providing lasting solutions to these problems and has the potential to impact on care for children in any setting, resources notwithstanding. Just as for its predecessor, Burkitt lymphoma, the importance and potential impact of the work by the Wilms collaboration is incontrovertible. "

SIOF – Poster Prize Dr Vivian Paintsil

Congratulations to Vivian Paintsil for writing and presenting a poster abstract at SIOF in Cape Town and winning the prize for the renal tumours section!

Vivian summarised that incomplete treatment is the most common cause for treatment failure, and that it is preventable. The main reason for incomplete treatment in most cases is that patients cannot afford the cost of treatment, which they are often 100% responsible for. Funding is needed to completely cover the cost of treatment for patients, as well as the supportive costs for the family such as accommodation and food. The aim of the collaboration is to reduce incomplete treatment to less than 10% of all cases. Our strategy includes funding treatment costs, providing adequate counselling for families and undertaking active follow-up for patients.



Dr Vivian Paintsil presenting the collaboration poster at SIOF 2015, Cape Town

Patient Story

This is Michael*, a patient at the Queen Elizabeth Central Hospital in Blantyre, Malawi. Michael has undergone surgery for a Wilms tumour and is now recovering on the ward with his grandmother by his side. Unfortunately Michael's parents have passed away so his grandmother has been staying at the hospital for the 3 months period of his treatment so far. She told us that as their home is some distance away near Lake Malawi; financial concerns, accommodation and food, as well as a lack of supplies are the main factors limiting the ability of the family to stay in the hospital.



Michael & his grandmother

* Patient's name has been changed to protect his identity

The collaboration partners and steering committee would like to thank all of our partners and supporters for your ongoing input into this work. Together we are pleased to be working step-by-step for these children with Wilms tumour in sub-Saharan Africa, and this would not be possible without your support.

If you have any questions please do not hesitate to contact the collaboration through our website:

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

Thank you!

Written by Liz Burns & Trijn Israels