



10% of children are affected by neurodisability...

...most live in Africa

INTRODUCING THE APFP

The African Paediatric Fellowship Programme (APFP) is building a workforce for specialist child healthcare for Africa, in Africa.

By the end of 2019, 116 health professionals from across the continent had completed the programme at the University of Cape Town. Of these, seven graduated as paediatric neurologists, with two due to complete their training in 2020.

Neurological diseases in African children differ from those seen elsewhere. Often layered with conditions like HIV, their treatment is especially complex, with common diagnoses including:

- Epilepsy (twice the global prevalence).
- Neuroinfection from malaria, TB and HIV.
- Cerebral palsy (often linked to poor obstetric care).
- Neuroimpairment caused by malnutrition.

Most countries do not have the resources they need to manage this burden of disease. Over and above a failure to prevent conditions, treatment and care is restricted by delayed diagnosis, access to facilities, and a lack of equipment/drugs.

These obstacles are compounded by chronic skill shortages, with studies counting <150 child neurologists across the continent for a population of over 600 million children. Instead, care is delivered by adult physicians with limited training in paediatrics – and, often, neurology.

The World Health Organisation (WHO) recommends one specialist neurologist per 100,000 children. The APFP supports this ambition and is working to build a critical mass of clinical and training expertise for paediatric neurology in Africa.

Each a catalyst for long-term change, the following case studies showcase the difference a single APFP fellow can make...



DR. ROBERT SEBUNYA

CONSULTANT CHILD NEUROLOGIST



2017-19

INTRODUCING DR. SEBUNYA

When he returned home in August 2019, Dr Sebunya became Uganda's fourth paediatric neurologist. Based at the St Francis Hospital, Nsambya, not only does he continue to work in general paediatrics, he is a pioneer of specialist services for children with neurological disorders.

ACTION PLANNING...

Paediatric neurology services in Uganda are limited, with children often referred to traditional healers or psychiatrists for care. According to Dr Sebunya, this can stem from the belief that such conditions are the result of witchcraft or possession – rather than a clinical diagnosis. It is an issue that motivated Dr Sebunya to specialise in paediatric neurology, and is one of the first areas he wants use his APFP training to address:

“Even the very educated still don't believe. People don't believe there is a medical condition that exists. It is witchcraft. We have a long way to go.”

■ COMMUNITY OUTREACH

Many of the children Dr Sebunya sees have been referred too late. Too often, their condition has progressed and caused irreversible damage. Prevention and early diagnosis is key. That is why Dr Sebunya plans to use social media, the radio and TV to raise awareness around the risk and reality of neurological disorders in children.

■ NEW SPECIALIST SERVICES

As service demand increases, Dr Sebunya wants to make sure the resources are there to meet it. So he's using his new skills to bring specialist care to the St Francis Hospital.

“My management approach to many general paediatrics and neurological clinical conditions has changed a lot for the better. I have also learned about many new, rarer disease conditions. My teachers were among the best I have ever come across! I am replicating what I learned from them.”

Taking referrals from across departments, Dr Sebunya has also launched a new neurology clinic. Open every Friday, the clinic saw 80-100 patients in its first four months. It now sees up to 20 patients *a week*. Thanks to his training, Dr Sebunya can also offer EEG testing and MRI scanning. Nerve conduction studies is next on the list.

■ BUILDING TRAINING EXPERTISE

Dr Sebunya also teaches at the medical school in Nsambya and Makerere University College of Health Sciences. Focussed on post-graduate paediatrics, he has integrated modules and clinical rotations on child neurology - giving students first-hand experience of cases that wasn't available before. He is also a faculty member for the Paediatric Epilepsy Training (PET) Ugandan Chapter, running a course for 25 delegates just weeks after returning home. Looking forward, Dr Sebunya also plans to introduce a short course in paediatric neurology – building capacity for professional development in-country and improving local case management.

■ A NETWORK OF CLINICAL EXPERTISE

As the eighth APFP fellow to qualify in paediatric neurology, Dr Sebunya is working to build informal connections using technologies like WhatsApp, so that alumni can quickly draw on each other's skills, experience and clinical expertise. He also joins his peers in a number of professional groups and activities, including the International League Against Epilepsy, PET training and cross-country research, an area in which he is keen to do more.

ON HIS TRAINING WITH THE APFP...

“The course was so so so helpful. I got to see a lot of things that I had never seen. But actually, the eye sees what it knows. These conditions were here at home! We didn't know. APFP helped me appreciate child neurology... There are many conditions that are now being solved, in the blink of an eye, that wouldn't have been solved before”.

DR. CHARLES HAMMOND
SENIOR SPECIALIST, PAEDIATRIC NEUROLOGIST



2014-17

A SPOTLIGHT ON DR. HAMMOND

Qualifying as a doctor in 2002, Dr Hammond trained with the APFP between 2014-17. Based at the Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana, he is one of 11 alumni selected by the hospital for training with the APFP – part of its ongoing plan to develop a multi-disciplinary, sub-specialist paediatric team.

SINCE HIS RETURN...

The second paediatric neurologist in the country, Dr Hammond’s department is the only one for families living in the central and northern parts of the country.

Today his team manage an estimated 600 in-patient and 2,000 out-patient visits a year. Caseload most often includes epilepsy and cerebral palsy, but infections like encephalitis, cerebral malaria and meningitis are not uncommon. Since his return, Dr Hammond has led on a number of critical service developments including:

■ **IMPROVED PATIENT CARE**

Dr Hammond has catalysed improvements in the treatment and management of common neurological conditions. He also notes an increase in the diagnosis of children with developmental conditions like autism and other, rarer, neurological disorders.

“My understanding of patient conditions has improved maybe over 100-fold... Even with common conditions, the clinical care has improved tremendously. I am also seeing rare conditions. Conditions that previously I wouldn’t think of.”

■ **EXPANDED EEG TESTING**

In 2019 Dr Hammond went on to expand and run the hospital’s first EEG clinic – one of just two for the whole of Ghana, and used to improve the diagnosis and treatment of conditions like epilepsy. Previously, it operated remotely, with readings sent to a centre in North America for analysis (a door opened by colleagues at the APFP). A second EEG machine was donated in April 2019. Thanks to his training with the APFP, these services are now in-house – with the clinic seeing 30-35 cases a month.

■ **EDUCATION AND TRAINING**

As well as building team capacity at KATH, Dr Hammond lectures at the University of Science and Technology, delivering generalist training and handling neurological aspects of the course. In 2018, he also took on the role of Country Lead for the delivery of Paediatric Epilepsy Training (PET). Organised by the British Paediatric Neurology Association and Paediatric Society of Ghana, this initiative has already trained a network of more than 200 in-country doctors.

■ **RESEARCH AND ADVOCACY**

Winner of the 2017 Bernard D’Souza Award, Dr Hammond is a member of six professional groups to further the agenda of paediatric neurologists at national and international levels - and provides crucial African representation on each. These include the International League Against Epilepsy where he is part of a taskforce to increase the availability of generic medication. He is also collaborating with the WHO on a project to understand the neurological impact of kangaroo care on children – and has more research in the pipeline.

ON HIS TRAINING WITH THE APFP...

“We share similar resource constraints with South Africa... That is the big plus for anyone working in my environment to train with the APFP. It makes you able to work where you are originally from. Training in other parts of the world coming back to settings like mine you have challenges... But I had mentors who understand the terrain, where I’ll be heading back to. They knew exactly what I was going to face”.

DR. EDWARD KIJA

CONSULTANT PAEDIATRIC NEUROLOGIST



2013-15

INTRODUCING DR. KIJA

The largest referral hospital in Tanzania, the Muhimbili National Hospital in Dar Es Salaam is a leading centre for paediatric neurological care. The first of two sub-specialist neurologists referred for APFP training by the hospital, Dr Kija's return was eagerly anticipated:

"When I came back they were waiting for me... I was very enthusiastic. Most of the things I learned in South Africa I knew I could implement at home. There were a lot of things I knew I could improve."

Graduating in 2015, during his time with the APFP Dr Kija developed the clinical, leadership and management skills he would need to drive long-term change.

■ DEDICATED NEUROLOGICAL SERVICES

The past three years have seen Dr Kija set-up a dedicated service for children with neurological conditions. Supported by a team of six doctors and up to four nurses at any one time, their eight paediatric beds are always full - with the team managing 600 in-patient and 5,000 out-patient visits every year. Every second child Dr Kija and his team see presents with either epilepsy or cerebral palsy. They are in the right place.

■ COUNTRY-LEADING CARE

Dr Kija has worked to expand EEG services from short to long-term testing. Determined to mirror

standards at the Red Cross Children's Hospital, he also helped his team of EEG technicians access formal online training.

This improved EEG testing service joins an impressive array of existing neurological facilities - from neuroimaging and MRI scanning, to laboratory, screening and rehabilitative services. There is nowhere else like it in Tanzania.

■ A NEW MULTI-DISCIPLINARY CLINIC

Building on the above, 2017 saw Dr Kija join forces with another APFP alumnus to launch a new multidisciplinary out-patient clinic for patients with neuro-muscular disorders. Unique in bringing neurologists, physiotherapists, occupational therapists and speech therapists together, it runs at least once a month and sees 5-10 patients each time.

■ FROM CONSULTANT TO EDUCATOR

Dr Kija was the first Tanzanian to be trained as a Paediatric Epilepsy Training (PET) facilitator, leading two courses in 2018 and another in 2019. Having reached 120 doctors so far, the next session is planned for 2020. As a Senior Lecturer at the Muhimbili University of Health and Allied Sciences Dr Kija is helping to train a new generation of paediatricians and also supervises 3-5 Masters students a year.

■ PIONEERING LONG-TERM CHANGE

Since returning from the APFP, not only has Dr Kija won the 2016 Bernard D'Souza award, he has contributed to the development of national guidelines for the management of paediatric diseases – advocating expanded guidance and standards in neurological care. He is a member of three national professional groups, is on various task forces for the International League of Epilepsy, and is a member of the executive board for the International Child Neurology Association. Like many APFP fellows, he is also involved in national, and multi-country research projects. This includes a new programme to build an in-depth picture of child onset epilepsy in Tanzania – a critical baseline for service and policy development.

ON HIS TRAINING WITH THE APFP...

"The experience that the APFP provides is very useful in terms of preparing fellows when they go back to implement what they've learned. You don't just learn clinical skills. It also helps you learn the management side of it, how to mobilise resources. That I think is a useful skill."

DR. PAULINE SAMIA

PAEDIATRIC NEUROLOGIST AND ASSISTANT PROFESSOR



2008-09

MEET DR. SAMIA

Dr Samia is one of the first fellows to have trained with the APFP. Graduating in 2009, she came to us from Gertrude's Children's Hospital, but has worked at the Aga Khan University Hospital since 2011. She will soon be joined by Dr Oyieke - the centre's second specialist paediatric neurologist. Together, they are two of nine APFP alumni based at the hospital.

CLOSING THE GAP

Working at Gertrude's new child development unit, Dr Samia applied to the APFP after seeing an important gap in clinical skills:

"They relied on an outsourced consultant. I saw a huge need. I was very aware of how limited my own knowledge and experience was. I was keen to get full credentials."

- A DECADE OF DEVELOPMENT

10 years since returning from the APFP, the ability to provide children with high-quality, clinical care is one of Dr Samia's biggest achievements.

Working across multiple wards, she sees 3-4 neurological in-patients every day, and 250 out-patients a month. They don't only come from Kenya. Often Dr Samia is examining children referred from hospitals in Uganda, Rwanda and Ethiopia.

"The fact that we can run this service - it's not for the country, it's for the region."

- A NEW IN-COUNTRY FELLOWSHIP

Dr Samia looks forward to a day when these centres have the resources to manage more cases in-country. That's why she is working with the Aga Khan University Hospital to launch their own fellowship for paediatric neurologists. In planning since 2014, the programme launches in 2020 and will start by training at least two fellows a year, more if the funding can be found. Once established, Dr Samia wants Aga Khan's fellowships to cater for other sub-specialities and health worker cadres - including children's nurses. Only then can optimal care ultimately be provided.

- ADVOCATING FOR CHILDREN'S RIGHTS

In addition to direct care, Dr Samia also strives to raise public awareness of neurological conditions, particularly among parents and family groups:

"Public awareness and knowledge in our set up is really poor. We've spent the last 10 years trying to improve education for doctors, but we also need to carry the parents with us... The parents, they too can push for the things children need, that we do not have, but they deserve."

An advocate for child rights, Dr Samia is also on the International League Against Epilepsy Paediatric Commission and International Child Neurology Association Executive Board. She also co-founded the Eastern Africa Academy of Childhood Disability – a regional faction of a larger, global movement. Having expanded membership to include Sudan, South Sudan and Djibouti, this team of dedicated professionals meet annually to forward their agenda and advocate the rights of children with disabilities.

- LOOKING FORWARD

In the next five years, Dr Samia wants to see the Aga Khan centre realise its vision to build a specialist children's hospital – one with the facility to offer every single speciality. She also wants to do more, collaborative research. Dr Samia is already working with her fellow APFP alumni to understand the status of paediatric epilepsy research in Africa. But this is just the start. There is so much more that needs to be done.

ON HER TRAINING WITH THE APFP...

"The people who were training you were really good at what they were doing. They knew their stuff, so to speak. The fact that UCT was able to provide a pathway to an academic qualification was helpful. I felt I could make a bigger impact."

OUR VISION | A GROWING AFRICAN NETWORK

WHAT NEXT FOR APFP NEUROLOGY?

APFP alumni are highly skilled clinical specialists, educators, researchers, advocates and leaders - a powerful force for long-term change. Delivering more than direct patient care, as these four case studies highlight, their impact has grown to include educational opportunity, systems change, research and policy development on a local, national and international stage.

“Together their stories represent an active and energetic collective transforming the level and quality of care for children with neurodisability in Africa.” Professor J. Wilmshurst, APFP Director

But whilst Africa’s pool of child neurologists has grown in the last 10 years, the world is still a long way from the WHO’s target of one specialist neurologist per 100,000 children. The APFP is proud to support this ambition and will continue to build both a critical mass of clinical expertise *and* partner capacity for the delivery of local, in-country training programmes.

As these achievements take place, the pace at which the paediatric skills deficit can be addressed will increase – with the APFP at the centre of a unique ripple effect that has the power to transform thousands of lives.

...of paediatric neurological expertise

FOR MORE INFORMATION

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PLEASE SUPPORT OUR WORK

It costs US\$30 000 a year to fully support the training of paediatric specialists like Dr Sebuya, Dr Hammond, Dr Kija and Dr Samia. Every dollar can help catalyse long-term change in the care of Africa’s children.

If you would like to donate, please visit:

The Children’s Hospital Trust
www.childrenshospitaltrust.org.za/donate
and choose the APFP.

