

Report

The orchestrated performance of the ICNA and first PET1 Course at the confluence of the Niles: Khartoum, January 2015.

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It has been a very busy start for the year 2015 here in Khartoum right at the confluence of the Blue and White Niles, whereby the first Paediatric Epilepsy Training Course Level 1 (PET 1), organized by the British Paediatric Neurology Association (BPNA) and sponsored by Sadaqat Charity Organization of Sudan, was first conducted at Soba Education Centre, Soba University Hospital, Khartoum on 27.1.2015. A very prestigious faculty arrived from UK, including the Executive Director of the BPNA, Philippa Rodie, Dr Sunny Phillips, from Birmingham NHS Trust, Dr Alice Jollands from Ninewells Hospital, Dundee and Dr Tark El Izzaby, United Arab Emirates. The Sudanese PET Facilitators arrived from Qatar (Dr Khalid Omer), United Arab Emirates (Dr Mohamed Elhadi Al-Malik) and in addition we had our local PET facilitators Dr Ahlam A. Hamed and Dr Inaam N. Mohammed from University of Khartoum.

The course was well attended by 48 general paediatricians who arrived to the Capital Khartoum

representing most Sudan provinces and the feedback was great. That was followed by the International Child Neurology Association (ICNA) Educational Meeting, held at Corinthia Hotel between 28.01.2015 and 30.01.2015, to which the PET Faculty contributed as well. There, we had a wealth of scientific plenary lectures presented by an international faculty like Dr Robin Rust from Virginia, USA who gave a lecture on hereditary metabolic diseases, and Dr Pratiba Singhi, from India, who gave lectures relating to CNS infections in the tropics. Prof Charles Newton gave an impressive talk about malaria and its CNS complications which was quite relevant to our setting. Dr Karen Skjei, from USA, gave a talk about recognizing common pediatric epilepsy syndromes [1] and another one on seizure semiology in infants and seizure mimics [2], and Prof Jo Wilmshurst, the Secretary of ICNA introduced us all to the ICNA and its free membership, and she gave a talk about management of neonatal and infantile seizures

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[3] and another one on the approach to status epilepticus in resource poor countries [4]. Dr Alice Jollands introduced us to the model of care used in rural Scotland and Dr Kirsty Donald, from South Africa, updated us about cerebral palsy (CP) status in Africa [5], while Dr Mohamed Elhadi Al-Malik, from United Arab Emirates (UAE), delivered a talk about pain in the disabled child “adding insult to injury” [6]. Learning difficulties in Sudanese children and the challenges faced in dealing with them were presented by Dr Aisha Mutwakel, a psychiatrist working in Khartoum [7]. Visually induced seizures was presented by Dr Imad Yassin, who came from UAE and neurocognition in epilepsy was presented by Dr Patrick Van Bogaert from Belgium [8]. Dr Sunny Phillips updated us on the ketogenic diet and Dr Khalid Omer, from Qatar, delivered a talk about seizures in special groups [9].

Mr El Fatih Bashir El Malik, Neurosurgeon (Sudan), delivered a talk about spinal cord schistosomiasis as a treatable cause of childhood paralysis in Sudan [10]. A disorder of ubiquitination leading to ataxia, dementia and hypogonadotropism was presented by Dr Ibrahim Adam from Jordan [11]. Dr Elsayed M. Ali (Saudi Arabia) talked about a case series of epileptic encephalopathies in early infancy with suppression-bursts EEG pattern [12]. Prof Mustafa Abdalla M. Salih presented an update on hereditary ataxias and spastic paraplegia in childhood [13], and had another talk on the diagnostic approach of the floppy infant syndrome [14].

Local papers regarding the paediatric neurology service and the pattern of the paediatric neurological disorders were presented by Drs Inaam M. Mohamed [15] and Maha Elseed [16]. Dr Ahlam A. Hamed presented a rare disease, sclerosteosis that occurred in 2 Sudanese families leading to the death of 2 out of 4 children affected with the disorder. The Sudanese Paediatric Neurology Group also presented a paper on the epidemiology of epilepsy among school children

in Khartoum State [17]. Professor Satti A. Satti, from Sudan, presented a case of acute disseminated encephalomyelitis [18]. Prof. Haydar El Hadi Babikir (Sudan) talked about the spiritual and traditional medicine among Sudanese children with epilepsy [19]. Dr Taher Obeid updated the audience on juvenile myoclonic epilepsy [20].

The Conference was sponsored by the Sudanese Association of Paediatricians (SAP) and was under the patronage of the Minister of Health, Khartoum State. There was a team of visiting speech and language therapists from London NHS Trust, represented by Tara Louviere and Aimee Cowen, as well as the occupational therapist Fiona Kingsley; the the neurodisability team being led by Dr Nazim Haydar Abdel Aati, a developmental paediatrician from London NHS Trust. Dr Nazim and the speech and language therapy team visited Sudan a few months ago and started to establish a program for training Sudanese speech and language therapists and performed several sessions geared towards training local disability teams as well as paediatricians in ways of assessment and management of children with feeding difficulties and communication disorders [21]. Dr Hayat osman Abdalla, Community and Developmental Paediatrician at East Nile Hospital, Khartoum State, was a great supporter and active member of the team. That visit occurred in August 2014 and lasted for 2 weeks, and involved visits to hospitals, neurology clinics, NGO sites offering physiotherapy services like Cheshire Home and OVCI as well as lectures to paediatricians and home visits. Following that visit, parents support groups started to be activated, a facebook page got established and they laid down the grounds for a visit that will involve professionals to lay out a Diploma in SALT as well as means of empowering our dedicated teams who are currently involved with these children. The challenging project which lies ahead now is the establishment of a CDC (Child Development Centre)

with all its supporting services. Dr Hayat Osman Abdalla (Sudan), Dr Nazim Haidar Abdel Aati (UK), Dr Haitham Albashir (Qatar) together with Tara, Aimee and Fiona did the Communication Disorders and Neurodisability sessions on the 29th and 30th of January 2015 to a targeted audience.

The social program was very vibrant and it included a Nile Cruise with lunch between 1200-1500 hours on Wednesday afternoon, and demonstration of our local heritage via Sudanese music and dancing of the Balimbo Band, wearing traditional costumes on the eve of the Opening Ceremony. There was a fish barbecue dinner along the banks of the Nile in Alhoush Restaurant that depicts Sudanese trends in everything from the waiters' dress, to the cuisine, dishes and wall decorations. Sanofi-Aventis sponsored one dinner party at Corinthia for all our prestigious guests. On the last day, more amusing moments were shared with yet another party at Dar Al-Naft, which overlooks the Blue Nile, again with dinner hosted by Khartoum State Ministry of Health. The greatest bit was the visit to Meroe Pyramids in Begrawiya (http://www.sudanjp.org/uploads/9/2/7/0/9270568/the_cover_sjp2011_no_1.pdf) on 31.1.2015 that ended with a nice Fish dinner after a dynamic trip in the unyielding African sun. The maestro to most of the programs was Prof. Haydar El Hadi Babikir, Paediatric Neurologist and Dean of the Faculty of Medicine, University of Gezira, Sudan.

A great deal of networking was achieved and a lot of future plans were discussed including fellowship program plans with South Africa. We are expecting PET 2 to be held in Khartoum next year after a successful PET1, and the BPNA has offered a 25% discount for Sudanese candidates on their Distant Learning Course that satisfies the European Training Advisory Board syllabus and involves 588 hours of study. Sadaqat Charity Organization, expectedly, offered to sponsor those interested to do the course.

That great work would not have been possible were

it not for Sadaqat and the enthusiasm displayed by its manager, Nazim Sirag and all the team behind the scenes. Our thanks extend to all our Residents and Medical Students and patients without whom all this was not going to be possible. Our thanks are extended to the Sudanese Association of Paediatricians, the Khartoum State Ministry of Health and to Al Nahda University, whose Dean, Dr Younis sponsored the boat lunch.

I leave you with the kind words that Dr Alice Jollands sent in an email after her safe arrival home, words that bring a lot of hope for our kids in Sudan.

“Just to say a big thank you for the privilege of teaching on the First PET course in Sudan and Africa. The local team's enthusiasm for improving epilepsy care and neurology service in Sudan is to be commended. With such dedication there can only be a brighter future for children with neurological diseases and children in general in Sudan. We have been treated like royalty and enjoyed your very warm and genuine hospitality. Thank your final year students for me and I wish most will stay in Sudan to contribute to the work being done there. Our thanks go to Sadaqat who worked so tirelessly to make it all happen including opportunities to gate crash weddings! One feels deeply humbled by such dedication to make Sudan a better place for all.

Dr Alice jollands
Consultant Paediatric Neurologist,
Tayside Children's Hospital,
Ninewells and the North East of Scotland Child and Adolescent Neurology Network (NESCANN).”

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