### **SAP President**

Prof Eisa O. Elamin FRCP, FRCPCH, DTCH

## **Vice-president**

Dr. Satti Abedelrheem Satti

**General Secretary** 

Dr. Ali Arabi

# **ORGANIZING COMMITTEE**

Dr. Ali Arabia Dr. Sati Abedelrheem

# **SCIENTIFIC COMMITTEE**

Prof. Musafa A. M. Salih Prof. Haydar E. Babikir Dr. Inam N. Gashe Dr. Ehlam Abedrhman Dr. Maha A. Elseed



At this point, the center of the Capital of Sudan [the three cities] the longest in the world; the River Nile starts its journey down stream to the Mediterranean ocean

This book was designed by Dr. Mustafa Haydar El Hadi M.BB.S (UofG)

# Message from the President of the Sudanese Association of Paediatricians (SAP)



We are privileged in SAP to host the ICNA conference in Khartoum. We are also lucky to have the BPNA Faculty representatives to do the PET1 course with this conference; the latter being held for the first time in Africa. SAP represents all paediatricians in the country and we hold annual scientific meetings in November. The last one was held two months ago and it was the 19<sup>th</sup>paediatric conference dedicated to touching on all issues related to child health. Subspecialties in Paediatrics including neuropaediatrics, are gaining momentum although late to start. This gathering will boost our efforts to establish them in full flesh.

Despite the global economic constraints and the Sudan is not exempt but our determinations are real and our hope for our dear children are without ceilings, especially that we are aware of our abilities, human and material resources. Our children deserve more than what we are doing both in the field of general paediatrics and its subspecialties. An international gathering such as ICNA and in the presence of the BPNA in Khartoum will be a great opportunity for our young paediatricians to witness state of the art talks and deliberations about important issues that help them to resolve patients' problems.

We in SAP are very proud of our fellow neurologists who are scratching stones with fingers at times to solve patients' problems in spite of meager supportive investigations and well established multidisciplinary care. We are here to support them endlessly.

We appreciate the presence of our honorable guests and we value their contributions to the scientific program and wish them a happy stay in this beautiful multi- ethnic country. We are looking forward to an entertaining social program including a cruise on the Nile and a visit to historic places. Khartoum offers a variety of African restaurants that serve appetizing local and international cuisines. The timing of the conference in January meant that our prestigious visitors will have a taste of our best weather as it is dry and the temperatures average 25-30°C. This together with the unyielding African sun is sure to be a unique start to 2015.

With my best wishes to you all.

Professor Eisa Osman El Amin MBBS, FRCP, FRCPCH, DTCH President of the Sudanese Association of Paediatricians (January 2015)

E-mail: eisaelamin@gmail.com

# Sudanese Society of Neurosciences (SSNS) President's Welcome speech



On behalf of the Sudanese Society of Neurological Sciences (SSNS), we would like to express our warmest welcome to scientists from USA, UK, Kenya, Belgium, India, South Africa and others. They came all the way at the expense of their precious time and the cost of travel.

Science is an international endeavor, and no nation could be successful in isolation. International exchanges and cooperation in neurology and other disciplines is of greater significance. I would like to express our warm welcome to the honorable guests, colleges and students participating in this teaching course.

During the past years the increasing numbers of members of SSNS confirmed that Neuroscience is flourishing in Sudan. The SSNS, as a society is growing and expanding into multidisciplinary fields, including Neurology, Neurosurgery, Neuro-paediatrics, Neurophysiology, Neuropathology, Neuroradiology, Neurootology, etc. More young physicians, scientists and students are joining the society, bringing fresh enthusiasm and new ideas. This is to emphasize our aspiration to improve all aspects of neurological care in Sudan through the promotion of correct scientific information.

This ICNA educational meeting has special flavor. This time being held in Khartoum added a tropical flavor from underprivileged country. We are confident that you will experience a meeting of high scientific quality where you will be able to gain and exchange new information about various pediatric neurological diseases.

I will leave the evaluation of the meeting for you, I'm sure it will have an international learning experience, but with an excellent Sudanese flavor.

I hope you will join us for a symphony of outstanding science and take a little extra time to enjoy the spectacular and unique beauty of Khartoum where the white and the Blue Nile meet.

In conclusion, I wish this meeting a great success, and hope that you all enjoy your stay in Khartoum.

With my best wishes

**Professor: Mohamed Nagib Abdalla Idris** 

The President of the SSNS

E-mail: nagib 01@yahoo.com

# **TIME TABLE**

	Day 1 28/01/2015
Nile Cruise	Gathering point: Corinthia Hotel at 11.00 am
20:00	OPENING SERMONY AT CORINTHIA LAPDHA
20:00-20:10	Pro. Eisa O. El Amin- President of Sudanese Association of Paediatricians (SAP)
20:10–20 :20	Prof. Mohamed Nageib President of Sudanese Society of Neuroscience (SSNS)
20:20-20:30	Prof. Zain A. Karrar President of Sudan Medical Council
20:3020: 40	Prof. Mustafa A. M. Salih on behalf of Sudanese Paediatric Neurologists
20:40- 20:50	Dr Layla Ali - president of the pediatric consultation committee.
20:50- 21:00	Prof. Jo Wilmshurst - Secretary International Child Neurology Association (ICNA)
21:00	Prof. Mammon M. A. Huomida - Minister of Health, Khartoum State, Sudan
21:20	Dinner

International Child Neurology Association Conferenceat Corinthia Hotel, Khartoum,

DAY 2 29/01/2015		
Chair Persons	Chair persons: Prof. Mustafa A Salih, Prof. Eisa Osman, Pro	f. Patrick Van Bogaert
8:00 – 9:00 am	Registration and Coffee	
9:00 – 9:20 am	Visually induced seizures and epilepsies	Imad Y Saadeldin
9:20 – 9:40 am	Approach to status epilepticus in resource poor countries	Jo Wilmshurst (South Africa)
9:40 – 10:00 am	Developing a model of care for resource poor countries based on a networked approach used in rural Scotland	Alice Jollands (Scotland)
10:00 – 10:20 am	Hereditary metabolic diseases	Robert Rust (USA)
10:20- 10:40 am	Juvenile Myoclonic Epilepsy	Tahir Obeid (Sudan)
10:40 – 11:00 am	Recent advances in management of bacterial meningitis and tuberculous meningitis	Singhi, Pratibha (India)
11:00 – 11:20 am	Approach to hereditary ataxias and spastic paraplegia in childhood	Mustafa A Salih (KSA)
11:20 – 11:40 am	CP in Africa: where we are?	Kirsty Donald (South Africa)
11:30 – 12:00 pm	coffee break	
Session 2	Chair persons: Prof. Zein Karrar, Prof. Singhi Pratibha, Prof.	
12:00 – 12:20 pm	Seizure semiology in infants and children and common seizure mimics	Karen L. Skjei (USA)
12:20 - 12:40 pm	Challenges of Practicing Learning Disability Psychiatry in Sudan	Aisha Motwakil Bakhiet (Sudan)
12:40 – 13:00 pm	Spinal cord schistosomiasis a treatable cause of childhood paralysis in Sudan	Alfatih Albashir Almalek (Sudan)
13:00 – 13:20 pm	Epilepsy and CNS infections	Singhi, Pratibha (India)
13:20 – 13:40 pm	Seizures in special groups	Khalid Omer (Qatar)
13:40 - 14:00 pm	Ketogenic Diet	Sunny Phillips (UK)
14:00 – 14:20 pm	Ataxia, Dementia, and Hypogonadotropism caused by Disordered Ubiquitination	Ibrahim Adam (Jordan)
14:20 - 14:35 pm	Pain in the neurodisabled child adding insult to injury	El Hadi Almalik (UAE)
14:35 - 15:00 pm	Lunch break and Networking	
15:00 - 17:30 pm	Workshop: Community paediatric management of neurodisability	Coordinator:- Dr Nazim Haidar Dr. K. Donald
20:00 pm	Social program	

DAY 3 30/01/2015			
Session 1 Chair persons: Prof. Salah M. Ibrahim, Prof. Ali habour, Dr. Sunny Phillips			
09:00 – 09:20 am	Diagnostic approach to the floppy infant	Mustafa A Salih (KSA)	
09:20 - 09:40 am	Recommendations to the management of neonatal and	Jo Wilmshurst (South Africa)	
	infantile seizures		
09:40 - 10:00 am	Challenges of learning difficulties in Sudan	Aisha Mutwakil (Sudan)	
10:00 - 10:20 am	CNS infections	Charles Newton (UK)	
10: 20 - 10:40 am	Neurocognitive development in paediatric epilepsy	Patrick Van Bogaert	
		(Belgium)	
10:40 - 11:00 am	Acute demyelinating encephalomyelitis in a four-year-old	Satti A. Rahim Satti (Sudan)	
	child		
11:00 - 11:15 am	Discussion		
11:15 - 12:00 am	Coffee break		
Session 2	Chair persons: Prof. Mohamed A. Abedalla, Prof. Mohamed Nagib, Dr. Kristy Donald		
12:00 – 12:20 pm	Recognizing common pediatric epilepsy syndromes	Karen L. Skjei (USA)	
12:20 - 12:40 pm	Ohtahara syndrome: case series	Alsyed M. Ahmed (KSA)	
12:40 – 13:35 pm	Lunch break and Networking and Gumaa' prayer		
13:35 – 13:50 pm	Clinical profile of neurological problems seen in	Inaam Nor eldyme Gashey	
	Sudanese children	(sudan)	
13:50 – 14:05 pm	Epidemiology of Epilepsy among School children in	Ahlam A. Rahman (Sudan)	
	Khartoum State in 2014		
14:05 - 14:20 pm	Traditional and Spiritual medicine among Sudanese	Haydar E. Babikir (Sudan)	
	children with epilepsy		
14:20 – 14:35 pm	Paediatric neurology service in Sudan: Current situation	Maha El Seed (Sudan)	
	and future challenges		
14:35 - 14:50 pm	Discussion		
15:00 - 17:30 pm	Workshop on Autism and Communication Disorders in	Dr. Nazim Hider	
	Childhood		
17:30 – 18:00 pm	Closure and feedback (Faculty)		
20:00-2200	Social program		

International Child Neurology Association Conference			
DAY 4	31/01/2015		
06:30 am-afternoon	TRIP TO PIJRAWIA	Gathering point:	Corinthia Hotel at 06:30 am
same day "in shaa Allah"	after Sobh' prayer		



# **CONFERENCE VENUE**

Nile Road, Khartoum, Sudan (Formerly Rickshaw / Burj Al-Fateh 18th floor) http://www.corinthia.com/hotels/khartoum/



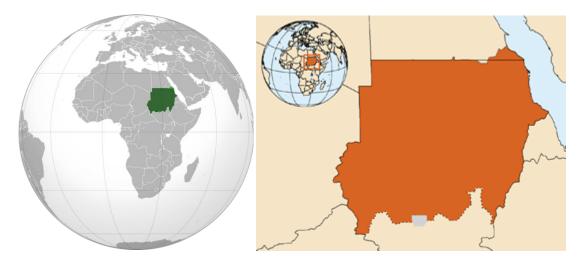






## **SUDAN AT A GLANCE**

**Sudan** is an Arab republic in the Nile Valley of North Africa, bordered by Egypt to the north, the Red Sea, Eritrea and Ethiopia to the east, South Sudan to the south, the Central African Republic to the southwest, Chad to the west and Libya to the northwest. It is the third largest country in Africa.



The country's place name *Sudan* given to a geographic region to the south of the Sahara, stretching from Western to eastern Central Africa



The predominant religion of Sudan is Islam. Its capital is Khartoum, the political, cultural and commercial centre of the. Sudan was the largest country in Africa and the Arab world until 2011, when South Sudan separated into a nation.



Khartoum Skyline

It is a federal presidential--independent country, following an independence referendum. Sudan is now the third largest country in Africa (after Algeria and the Democratic Republic of the Congo) and also the third largest country in the Arab world (after Algeria and Saudi Arabia).

Sudan was home to numerous ancient civilizations, such as the Kingdom of Kush, Meroe and others, most of which flourished along the Nile River. During the predynastic period Nubia and Nagadan Upper Egypt were identical, simultaneously evolved systems of pharaonic kingship by 3300 BC.



The large mud brick temple, known as the shrek or Western Deffufa, in the ancient city of Kerma

By the eighth millennium BC, people of a Neolithic culture had settled into a sedentary way of life Neolithic people moved to the Nile Valley along with agriculture during the fifth millennium BC.

The population that resulted from this cultural and genetic mixing developed social hierarchy over the next centuries became the Kingdom of Kush (with the capital at Kerma) at 1700 BC. The Kingdom of Kush was established after the Bronze Age. The Kushite kings ruled as Pharaohs of the Twenty-fifth dynasty of Egypt for a century before being defeated and driven out by the Assyrians.



Nubian pyramids in Meroë The Kingdom of Kush

#### **Christianity and Islam in Sudan**

By the 6th century, fifty states had emerged as the political and cultural heirs of the Meroitic Kingdom. A missionary sent by Byzantine empress Theodora arrived in Nobatia and started preaching Christianity about 540 AD.



### Fresco of Faras Cathedral, 10th-11th century

After failure of many military attempts, the Islamic Arabin Egypt and the Nubians had treaties known as *al-baqt* (pactum) that governed between the two peoples for more than 678 years. Islam progressed in the area over a long period of time through intermarriage and contacts with Arab merchants and settlers.

During the 16th century in southern Nubia the Funj appeared and succeeded the remnants of the old Christian kingdom of Alwa, establishing As-Saltanaaz-Zarqa, [the Sultanate of Sennar].

**During** (1821–1885)the Wāli of Egypt under the Ottoman Sultan, Muhammad Ali who styled himself as Khedive of a virtually independent Egypt sent 4,000 troops to invade Sudan, conquered the country, and subsequently incorporated it into Egypt.

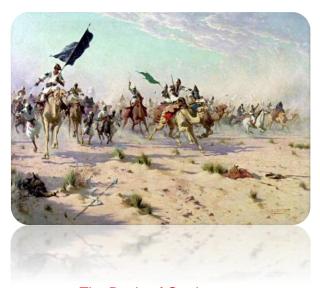






Suakin National Bank

In June 1881 until the fall of Khartoum in January 1885, Muhammad Ahmad Al Mahdi led a successful military campaign against the Turco-Egyptian government of the Sudan. He died on 22 June 1885, a mere six months after the conquest of Khartoum. Between 1896 to 1898, Lord Kitchener led the British military campaigns against the Mahdists. Kitchener's campaigns climaxed in the Battle of Omdurman on 2 September 1898. The Mahadists where the first to breach and break-through to the centre of the famous British Square. (A defensive formation used by the infantry, each side of the square would contain two lines of troops. The first would kneel with bayonets raised, the second would stand and fire.) This formation had never been broken until the *fuzzy-Wuzzies* (Dervish warriors) in the battle of Abu Klea (http://allpoetry.com/Fuzzy-Wuzzy). Thereafter an Anglo-Egyptian control over the Sudan began.



The Battle of Omdurman

The Egyptian Revolution of 1952 finally heralded the beginning of the march towards Sudanese independence in Jan. 1<sup>st</sup>, 1965.



Sudan's independent (old flag) raised at independence ceremony on 1 January 1956 by the Prime Minister Ismail Al Azhari and the leader of opposition party Mohamed A. El Mahgoub

**Economy:** Sudan is rich in terms of natural and human resources, but it is a low-income country. Agriculture production remains Sudan's most-important sector. Agricultural activity provides a livelihood for 70% of the workforce and contributes thirty-nine percent of GDP, but its contribution to the GDP has decreased from 46.3% in 2000 to 39% in 2005 as most farms remain rain-fed and susceptible to drought. Oil was Sudan's main export, with production increasing dramatically during the late 2000s, in the years before South Sudan gained independence in July 2011.

**Culture:** Sudanese culture melds the behaviors, practices, and beliefs of about 578 ethnic groups, communicating in 145 different languages, in a region microcosmic of Africa, with geographic extremes varying from sandy desert to tropical forest.

Sudan's main health status indicators (national and south Sudan)

**Demographic indicators [before South Sudan separation]** 

Crude birth rate (%0)	37.8
Crude death rate (%0)	11.5
Total fertility rate (per woman)	5.9
Life expectancy at birth (years)	56.6
Infant mortality rate (per 1000 live births)	81
Under five mortality rate (per 1000 live births)	112
Maternal mortality ratio (per 100 000 live births)	1107

Source: UNFPA. Situational analysis of reproductive health and adolescent sexual

and reproductive health in South

Sudan, April 2007

Capital		Khartoum 15°38'N 032°32'E	
Government		Federal presidential rep	ublic
Legislature		National Legislature	
Formation			
-	Nubian kingdoms	3500 BC	
-	Sennar dynasty	1504 <sup>[4]</sup>	
-	Unified with Egypt	1820	
-	Anglo-Egyptian Sudan	1899	
-	Independence (from the UK and Egypt)	1 January 1956	
Area			
-	Total	1,886,068 km <sup>2</sup> 728,215 sq mi	(16th)
Population			
-	2014 estimate	37,289,406 <sup>[5]</sup> (35th)	
-	2008 census	30,894,000 (disputed)	) <sup>[6]</sup>
-	Density	16.4/km <sup>2</sup> 42.4/sq mi	
Time zone		East Africa Time (UT	C+3)
Drives on the		Right	
Calling code		+249	
ISO 3166 code		SD	
Internet TLD		.sd, سودان	



Dinder's National Park

### **BIOGRAPHIES**

#### **Professor Jo Wilmshurst**



Professor Jo Wilmshurst is Head of Paediatric Neurology at the Red Cross War Memorial Children's Hospital, University of Cape Town, in South Africa. She is a member of the executive board of the Paediatric Neurology and Development Association of Southern Africa (PANDA-SA) and the African Child Neurology Association (ACNA). She is Secretary of the International Child Neurology Association. She is chair of the Commission on Paediatrics for the International League Against Epilepsy (ILAE) (2013-2016) and Education officer for the Commission on African Affairs. She is director of the African Paediatric Fellowship Program – a training program under the auspices of the University of Cape which aims at developing skills in paediatric disciplines of doctors from across Africa. She is an associate editor for Epilepsia and on the editorial board for the JICNA, the Journal of Child Neurology, Epileptic Disorders. Seizure and is a regional co-Editor for Epileptology. She has over 60 peer reviewed publications. She has interests in rare neurological disorders, such as neuromuscular diseases and neurocutaneous syndromes, and common high impact diseases, such as epilepsy and neuroinfections. Her work ethos is aimed towards developing improved care for children with neurological diseases in South Africa through the specialist services in her centre, training of health care specialists, the development of rational management templates which are viable in the African context, and the adaption of international recommendations.

E-mail: Jo.wilmshurst@uct.ac.za



#### **Prof. Pratibha Singhi**



Prof. Singhi is currently Professor and Chief, Pediatric Neurology and Neuro-Development in the Department of Pediatrics, Advanced Pediatrics Centre, Post Graduate Institute of Medical Education and Research Chandigarh. She is also the Honorary Consultant In-charge at Prayas –the Rehabilitation Centre for Disabled children, Chandigarh since 1985. She has also worked as locum consultant Neurologist at the Great Ormond Street Hospital, London in 2005 and 2008.

#### **Research Interests**

Has done original research in the field of CNS infections, Epilepsy, Neuro-developmental disorders including autism, cerebral palsy and ADHD etc.

She has conducted several research projects including those from WHO, ICMR, ICSSR, PGI, and INDO UK collaborative project. Currently working on INDO-EU Project and an INDO-Swedish Project.

**Contributions to Pediatric Neurology and Neurodevelopment** 

- Started DM Pediatric Neurology Course 2011
- Total Publications- = 289 plus 4 books Books written / edited:
- 1. Central Nervous System Infections in Childhood. Eds. Pratibha Singhi, Diane E Griffin and Charles R Newton. International Review of Child Neurology Series. Publisher Mac Keith Press, Oxford, UK, 2014.
- 2. Neurology section of IAP Textbook of Pediatrics 2013, published by Jaypee Brothers, Medical Publishers (P) Ltd., New Delhi
- 3. Seizures and Epilepsy in Children A Practical Guide. Published by Noble Vision, 2009.
- 4. Pediatric Neurology and Epilepsy Nov 2009 (Based on Proceedings of International Conference of Pediatric Neurology and Epilepsy)

#### Academic Awards/ Fellowships

- Rotary International Foundation Graduate Fellowship, University of Southern California Los Angeles, U.S.A.
- James Flett Gold Medal of IAP- 1987 for best research paper in Social Pediatrics.
- **Heinz Fellowshipof the British Pediatric Association** in Pediatric Neurology, Epilepsy and Neuro-Development at (i) The Royal Hospital for Sick Children Edinburgh, UK and (ii) The Royal Victoria Infirmary New Castle, U.K. in 1991.
- WHO Fellowship Thailand & Nepal, 1991.
- Fellowship in Pediatric Neurology and Epilepsy at Johns Hopkins Hospital and Neuro-Development at Kennedy Krieger Institute, Baltimore, USA in 1991-92.
- Fellowship of Indian Academy of Pediatrics.
- Best paper first prizes at IAP Pedicon, 1994, 1998
- Visiting fellowship of the Royal College of Pediatrics and Child health London UK 2000-for Pediatric Epilepsy and Neurology.
- **Nehru Chair Visiting Professorship** M.S. University Baroda 2001.
- Asian Research Award at the 6<sup>th</sup> Infantile Seizure Society at Tokyo, March 2003.
  - A) Research papers in PEER REVIEWED INDEXED Journals
- "Medical Scientist Award" by DrShurvir Singh Trust, Rajasthan for 2002-03 for outstanding contributions in Medical Sciences especially in Pediatric Neurology, Epilepsy and Neurodevelopment.
- Visiting Professor to Karolinska Institute, Stockholm, Sweden, 2012
- Awarded the S. Janaki Memorial Oration by the National Academy of Medical Sciences (2013) for outstanding contribution to Pediatric and Adolescent Neurology.

E-mail: doctorpratibhasinghi@gmail.com

ns	
National	125
International	134
Chapters in Books	30
Books	4

#### Alice Jollands



Dr Jollands trained as a general paediatrician, subsequently further specialising in neurodevelopmental paediatrics and then child neurology in South Africa. She was a senior lecturer and consultant at the Tygerberg Children's Hospital and University of Stellenbosch near Cape Town before relocating to Scotland in 2003. She currently works as one of two consultant child neurologists providing tertiary level neurology services to the North of Scotland in the context of a clinical network. She is an honorary lecturer at the University of Dundee Medical School. She is a fellow of and an examiner for the RCPCH and an active member of the BPNA. She has taught nationally and internationally on the BPNA PET 1, 2, 3 and CHAT courses.

E-mail: <u>alice.jollands@nhs.net</u>

### **Kirsty Donald**



Dr Donald is a Paediatric Neurologist with an interest in the developmental disabilities as they manifest and are managed in resource limited settings such as South Africa. Specific interests include the preventable causes of neurodisability such as alcohol and methamphetamine exposure, organophosphate poisoning and the neurological and neurocognitive complications of HIV. She leads a clinical service which sees approximately 4000 children with developmental problems and neurodisability every year. Dr Donald is secretary of the South African Paediatric Neurology and Development Association. She is actively involved in current research projects across all of the fields listed above with collaborations locally and internationally and is involved with both undergraduate and post-graduate supervision and training.

e-mail: kirsty.donald@uct.ac.za



## Professor Mustafa Abdalla M. Salih



- ☐ Biography links:
- 1) http://faculty.ksu.edu.sa/66414/default.aspx
- 2)http://biography.marquiswhoswho.com/pediatric-neurologist/mustafa-abdalla-mohamed-salih/5059399
- 3)https://www.researchgate.net/profile/Mustafa\_Salih/?ev=hdr\_xprf
- Pediatric neurologist *Mustafa Abdalla M. Salih* was born in Kosti, White Nile Province, Sudan.
- ☐ Professor Salih earned an MBBS degree in 1974, an MPCH degree in 1980 (renamed MD in Clinical Pediatrics),
- a Doctor of Medicine with Distinction in 1982, all from the University of Khartoum.
- ☐ He also earned a Doctor of Medical Sciences in 1990 from Uppsala University in Sweden.
- ☐ In 2005, he was elected Fellow to The Royal College of Paediatrics and Child Health (FRCPCH, UK).
- □ Currently, Prof. Salih serves as Professor of Pediatrics and Consultant Pediatric Neurologist at the College of Medicine, King Saud University, Riyadh, Saudi Arabia.
- ☐ He previously served as Lecturer, Associate Professor and Professor of Pediatrics with the Faculty of Medicine at the University of Khartoum in Sudan from 1980 to 1992.
- ☐ He has published (as of March 2014) 176 scientific articles in peer-reviewed medical journals, two supplements in the Scandinavian Journal of Infectious Diseases and the Saudi Medical Journal. He also authored two chapters in the textbook, Genetic Disorders among Arab Populations (two editions: 1997 and 2010), one chapter in the textbook, Diseases of DNA Repair (2010) and seven chapters on pediatric neurology in the Textbook of Clinical Pediatrics (2012).
- ☐ He is a former editor of the Sudanese Journal of Pediatrics (1985-91), a former member of the editorial board of the Sudan Medical Journal (1983-86) and Guest Editor to a Saudi Medical Journal Supplement (March 2006). Currently, he is the International Editor of Sudanese Journal of Paediatrics and Sudan Medical Journal. He is also a member of the editorial boards of The Journal of Pediatric Neurology, The Open Pediatric Medicine Journal and The Open Neurology Journal; and Member of the Advisory Board of the Journal of Taibah University Medical Sciences.
- ☐ He holds a United States patent on a diagnostic method for congenital muscular dystrophy, and has evaluated new techniques for the rapid diagnosis of bacterial meningitis.
- □ Prof. Salih was awarded the President of Sudan Prize for Distinguished Students in 1964, 2 awards from the Faculty of Medicine at the University of Khartoum, the Riyadh Neuroscience Award in 1996, the Medal of Excellence by the President of Sudan in 2007, and The Saudi Neurosciences Society Award for Pioneers and Promoters of Neurosciences in Saudi Arabia in 2008, King Saud University Gold Medal in 2010, and King Saud University Lifetime Scientific Achievement Award in 2014.
- ☐ His biography is listed in numerous International Biographical Centre, American Biographical Institute, and Marquis' Who's Who publications.

E-mail: mustafa salih05@yahoo.com

## **Professor Charles Newton**



Professor Charles Newton MBChB, MRCP, MD, FRCPCH Kenya Medical Research Institute, Kilifi, Kenya Cheryl and Reece Scott Professor of Psychiatry, University of Oxford, United Kingdom

Charles Newton was born in Kenya. He qualified in Cape Town, South Africa, with postgraduate training in Paediatrics in Manchester and London, United Kingdom. As a lecturer at University of Oxford, he returned to Kilifi in Kenya, to help set up a unit to study severe malaria in African children. Thereafter he spent 2 years as a Post-doctoral fellow at Johns Hopkins, USA; studying mechanisms of brain damage in central nervous system infections. He completed his training in Paediatric Neurology at Great Ormond Street Hospital, UK. In 1998 he was awarded a Wellcome Trust Senior Clinical Fellowship at University College London, to return to Kilifi, to study CNS infections in children. He became Head of Clinical Research in Kilifi, and has published on a wide variety of subjects concerning sick children in tropical countries. He set up the first study that showed the association between epilepsy and falciparum malaria. In 2008 he set up a study to survey epilepsy in five countries in Africa. He and his colleagues surveyed over 600,000 people in East, South and West Africa for active convulsive epilepsy. In 2011 he took up a professorship in Psychiatry at the University of Oxford to concentrate of neurological and mental illness disorders in Africa.

E-mail: <u>CNewton@kemri-wellcome.org</u>

# Karen L. Skjei Curriculum Vitae/Bibliography

Karen L. Skjei, M.D.





#### 1. PERSONAL INFORMATION

Place of Birth: California Citizenship: United States

Contact

Information: 601 Floyd St, Suite 500

Louisville KY 40202 (502) 588-3650 (502) 588-7852 fax

#### 2. MEDICAL LICENSURE& BOARD CERTIFICATION

10/2013 ACNS, Clinical Neurophysiology Certification with Specialization in

Epilepsy Monitoring, exp 10/2014

10/2013	APBN, Epilepsy Certification, exp 10/2014	
7/2012	Kentucky, License # 45473	
9/2010	ABPN, Neurology with Special Certification in Child Neurology, Exp	
	12/2020	
2010-present	Pennsylvania, License # MD439589	
2005-2010	Minnesota, License # 48761	
PRESENT ACADEMIC RANK AND POSITION		

3. P

2012 - Current Assistant Professor, University of Louisville, Pediatric Neurology

Director, Epilepsy Monitoring Unit, Kosair Children's Hospital

Louisville, KY

2010 - 2012Fellow, Clinical Neurophysiology and Epilepsy

Children's Hospital of Philadelphia

Philadelphia, PA

Instructor, Neurology 2009-2010

> Mayo Clinic Rochester, MN

2007-2010 Fellow, Child and Adolescent

> Neuroloav Mayo Clinic Rochester, MN

Resident, Pediatrics 2005-2007

> Mayo Clinic Rochester, MN

E-mail: karen.skjei@louisville.edu

## **CRRICULUM VITAE** Patrick VANBOGAERT





Date of born: 19 May1963 Medical doctor graduate at the Université Librede Bruxelles (ULB), Belgium (1987). Agreements in Neurology (1992) and Pediatric Neurology (1998). PhDthesisin1998attheULB. Professor in Pediatric Neurology at the ULB. Head of the department of Pediatric Neurology and co--director of the "laboratories Decor tographiefonctionnelleducerveau" at Erase University Hospital (ULB), Brussels, Belgium President of the Belgian League Against Epilepsy. Secretary of the ILAE Pediatrics Commission Author or co—author of 120 medical peer—reviewed articles. Authorof2bookchaptersonepilepticencephalopathywithcontinuousspike---waves During slow---wave sleep.

E-mail: <a href="mailto:pvanboga@ulb.ac.be">pvanboga@ulb.ac.be</a>

## Tara Rae Louviere



Tara has a MSc in speech and language therapy from Reading University. She works as a speech therapist in the NHS for the North East London Foundation Trust (NELFT). She works in the Child Development Team with children under 5 with autism and complex needs. Tara works with children who have difficulties with their communication and/or their eating and drinking. Tara also works in special schools with older children who have difficulties with eating and drinking. Before training as a speech therapist Tara was a teacher of children with special needs. Tara is registered with the HCPC (Health Care Profession's Council) and is a member of the RCSLT (Royal College of Speech and Language Therapists).

## **Aimee Jonne Cowen**



Aimee has a BSc in speech and language therapy from City University, London. She works as a speech therapist in the NHS for the North East London Foundation Trust (NELFT). She works in the Child Development Team with children under 5 with autism and complex needs. Aimee works predominately with children with communication difficulties. Before starting at NELFT Aimee worked as a clinical research assistant, though originally she has a background in Theatre. Aimee is registered with the HCPC (Health Care Profession's Council) and is a newly qualified member of the RCSLT (Royal College of Speech and Language Therapists).

# Prof. Tahir Obeid. F.C.R.P (U.K).F.A.A.N.



Prof. Neurology –University of Medical Science & Technology, Khartoum. Consultant Neurologist & Epilepiologist, Alzaytuna Academic and Hospitals, Khartoum. Member of Faculty of 1000-International League Against Epilepsy. More than 55 publications in Internationals Peer View Journals mainly in Epileptiology.

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# Dr. SattiAbdelrahimSatti.MD, ABPed



- Associate Professor & Pediatric Consultant.
- Subespeciality in Pediatric Infectious Diseases and Tropical Pediatrics.
- Degrees: M D in Pediatrics. Arab Board in Pediatrics.

- Now Head of Pediatric Department in Alaml National Hospital.
- Partier with Faculty of Medicine, University of Khartoum.
- Convenor of the Pediatric & Child Health Council at Sudan Medical Specialization Board (SMSB)
- More than fifteen published original articles & case reports.
- One of the Editors of Sudanese Journal of Pediatrics.
- A member of the Ebola Consultancy Committee

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# Dr. El-Sayed Ali FRCPI, DCH, DipNeuro (Lond)

Consultant Pediatric Neurologist Director, Clinical Neurosciences Department **KFMMC**, **DHAHRAN** 



Dr Ali graduated from Khartoum University (Sudan) in 1980, and completed residency training in pediatrics in Suleimania Children Hospital, Riyadh. After that I obtained the Membership & Fellowship of Royal College of Physicians in Ireland.

He was appointed as Consultant Pediatrician in Suleimania Children Hospital & Clinical Assistant Professor from King Saud University between 1994 and 1998.

Dr. Ali was trained in Pediatric Neurology & Neurophysiology in King Saud University, Riyadh and University College London (Great Ormond Street Children Hospital and Institute of Neurology, Queen Square).

After that he joined King Fahd Military Medical Complex Dhahran as consultant pediatric neurologist. Over the last 15 years, He actively participated in establishing the Child Neurology Service in the KFMMC hospital, which is a very busy service that also serves children, referred from different military hospitals in the eastern province of KSA Dr. Ali participated as guest speaker in many national and international neurology conferences, and he published articles in the field of pediatric neurology in national and international journals.

Main areas of interest are epilepsy, neuromuscular disorders and movement disorders.

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## Mohamed-Elhadi Al-Malik M.D.



#### Trained in:

• Khartoum Teaching Hospital, University of Khartoum, Sudan (Paediatric Master Program)

- King Khalid University Hospital, Riyadh (Arab board program)
- Kettering General hospital (Oxford Deanery rotation) UK
- University hospital of Leicester (Children's hospital, Leicester Royal infirmary) UK

#### **Qualifications:**

- Mb Bch Faculty of Medicine Cairo University
- Membership of the Royal college of Physicians UK
- Membership of the Royal college of Paediatrics UK
- Fellowship of the Royal college of Paediatrics UK
- Certificate of completion of specialised training (CCST) UK
- Postgraduate diploma in Clinical sciences Leicester University UK

#### **Previous Job:**

Consultant and clinical senior lecturer, Sheffield University UK

#### **Current:**

- Senior consultant paediatrician and child Neurologist, and head of Paediatric neurology Division Tawam hospital, Al Ain
- Clinical Assistant professor, Faculty of Medicine, UAE University.
- Paediatric CME director, Tawam hospital, Al Ain
- External Examiner for the membership of the Royal college of Paediatrics (MRCPCH) and postgraduate diploma in paediatrics and Child Health, (DCH) UK
- Instructor International Paediatric epilepsy training course (IPET)

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## **Khalid Omer Ahmed Ibrahim**



#### **Current Position:**

**Senior Consultant / Head** of Paediatric Neurology Division; Hamad Medical Corporation (HMC), Qatar **Assistant Professor** of Paediatrics, Weill Cornell Medical College, Qatar

Trained in Paediatric Neurology in the UK

Worked as a consultant Paediatric Neurology in Edinburgh and London (UK) before joining HMC

Qualification: MBBS, MD, FRCPCH, FRCP, CCST (UK)

CCST: Certificate of Completion of Higher Specialist Training (UK)

FRCP: Fellow of the Royal College of Physician of Edinburgh, UK 2010

FRCPCH: Fellow of the Royal College of Paediatrics and Child Health, UK 2006

MD: Medical Doctorate in Paediatrics, University of Khartoum, Sudan

MBBS, Faculty of Medicine, University of Gezira, Sudan

Member of the British Paediatric Neurology Association

#### **Practice License:**

General Medical Council (UK)

Supreme Council of Health, Qatar

Sudan Medical Council

Clinical Interest: Acute Neurology; Complex Epilepsy and Movement Disorders.

**Publications (selected):** 

- Elsaid MF, Kamel H, Chalhoub N, Aziz NA, Ibrahim K, Ben-Omran T, George B, Al-Dous E, Mohamoud Y, Malek JA, Ross ME, Aleem AA (2014) Whole genome sequencing identifies a novel occludin mutation in microcephaly with band-like calcification and polymicrogyria that extends the phenotypic spectrum. Am J Med Genet A 164A:1614-1617
- 2. Haberle J, Shahbeck N, **Ibrahim K**, Schmitt B, Scheer I, O'Gorman R, Chaudhry FA, Ben-Omran T. Glutamine supplementation in a child with inherited GS deficiency improves the clinical status and partially corrects the peripheral and central amino acid imbalance. Orphanet J Rare Dis, 7 (1), 48 (in press).
- 3. **Ibrahim K**, Russell G, Cahill D, Ahmed M. Chvostek's sign in childhood headache. Journal of Pediatric Neurology. 2011; 9(1):23-7.
- 4. Haberle J, Shahbeck N, **Ibrahim K**, Hoffmann GF, Ben-Omran T. Natural course of glutamine synthetase deficiency in a 3 year old patient. Molecular Genetics and Metabolism. 2011 May; 103(1):89-91.
- 5. Drew B, **Ibrahim K**, Reddy MA. Herpes zoster ophthalmicus complicated by incomplete ophthalmoplegia and a neurotrophic ulcer. Eye (Lond). 2009 Aug; 23(8):1752-3.
- 6. Diagnosis and management of epilepsies in children and young people. Edinburgh, UK: 57 p. Scottish Intercollegiate Guidelines Network; 2005 Mar. Report No.: 81.
- 7. **Ibrahim K**, Appleton R. Seizures as the presenting symptom of brain tumours in children. Seizure. 2004 Mar; 13(2):108-12.

#### **Research Involvement:**

Principal investigator in 4 major projects

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# Prof. Haydar El Hadi Babikir MD



- Prof. Haydar El Hadi Babikir MD, is a professor of Paediatric and Child Health/Neurology, Faculty of Medicine, University of Gezira, Sudan
- Prof. Babikir was born in the Gezira State, Central Sudan, married and a father of 3 girls and one son
- A graduate of Faculty of Medicine University of Khartoum in 1980
- Completed his graduate studies and specialized in Paediatric and Child Health in 1990 in the Faculty of Medicine, University of Khartoum
- Worked as specialist in general pediatrics at Port Sudan Teaching Hospital till 1994
- He joined the Faculty of Medicine, University of Gezira FOMG in 1994
- Had been promoted to associate professor of Child Health in 2006, and the head department of Medical Postgraduate studies in FOMG.
- Prof. Babikir was promoted to professor of Paediatrics and Child Health in 2011 currently he is the dean of the FOMG.
- He was trained in paediatric neurology at Ege University, Izmir, Turkey and at the General Hospital and Victoria Royal infirmary in N' Castle upon Tyne and Children Royal Hospital in Manchester, and Hope Hospital Salford Manchester U.K.
- He was attended many comprehensive courses on Epilepsy and EEG at the Army Force Hospital, Riyadh, Kingdom of Saudi Arabia and at All India Institute of Medical Science (AIIMS), New Delhi, India and the PET1, PET2 PET3 and the EEG course (BPNA).
- He also attended and participated in a number of conferences on clinical neurology at UCL, Manchester, Edinburgh, Winchester, U.K., in Riyadh, KSA, and Ankara, Turkey

- As an active member of ICNA and ACNA he participated by scientific works in all their joint annual workshops and conferences.
- He is an active member of British Paediatric Neurology Association (BPNA) and the European Paediatric Neurology Society (EPNS) Sudanese Society of Neuroscience (SSNS) African Child Neurology Association (ACNA) and the Sudanese Association of Paediatricians (SAP).
- He was awarded the certificate of the American Academy of Continuous Medical Education on Epilepsy.
- Prof. Babikir was trained at the Institute for Children with Special Needs in Kitakyausa, Japan and he is a cofounder and currently the president of Wad Medani Charity Society and School for Children with special needs.
- He wrote and published many original, case reports and review articles in Paediatric neurology.
- He is an author of the Childhood Epilepsies and epileptic syndromes textbook

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# Dr. Haitham El Bashir MRCP (UK), FRCPCH, DCH, CCST, MD (Lond.)



Dr El Bashir is a senior consultant & Head of Children Rehabilitation Section at Hamad Medical Corporation (HMC) and associate professor of clinical paediatrics at Weill Cornell Medical College-Qatar. He is a fellow of the Royal College of Paediatrics and Child Health, UK. He was recently appointed as the Division Chief for Rehabilitation Medicine at Sidra Medical and Research Center in Qatar.

Dr El Bashir graduated in 1994 from Khartoum University (Sudan) with distinction and university prize in paediatrics. He trained in the United Kingdom and completed his training (CCST) in 2005. He worked as a consultant paediatrician in Great Ormond Street Hospital in London and subsequently a senior lecturer at the Institute of Child Health, University College London.

Dr El Bashir joined HMC in 2008 as a senior consultant and in 2009 he became the head of the Children Rehabilitation Section. In 2010, he established the Child development Center, a dedicated facility for children with developmental disorders and rehabilitation needs. The center encompasses out-patient clinics, day programs as well as specialised clinics and services.

Dr El Bashir has led many committees within the pediatric department and HMC including: Chair of the Child development & Rehabilitation relocation task force, Chair of the Clinical Practice Guidelines (CPG) Committee (Rumailah Hospital), Chair of the Child Health Research Committee & taskforce in HMC and chair of pediatric faculty development.

Dr El Bashir is actively involved in supporting and delivering the education curriculum for the paediatric department. He has extensive experience in teaching in both undergraduate and postgraduate settings. In 2008, he established the first Developmental Pediatric & Children Rehabilitation fellowship program and he was the fellowship director till July 2011.

Dr El Bashir main research interest is in epidemiology. In 2009, he has successfully completed a research MD doctorate thesis from University of London, UK. He has published in many peer-review journals.

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# Dr. Imad Yassin Saadeldin, MD





Dr. Saadeldin obtained his MD in pediatrics in 1994 from Vienna and Graz Universities, Austria, and the Fellowship in Pediatrics and Adolescent Medicine from the Austrian Medical Association, Vienna, Austria. He did his postgraduate training in pediatric neurology at the Pediatric Neurology department, Graz University Hospital, Graz, Austria. He obtained his membership from the Royal College of Pediatrics and Child health from UK on 2004. He was Consultant Pediatric Neurologist and the head of Pediatric Neurology Division at Armed Forces Hospital, Southern Region, Saudi Arabia from 2005-2011 and Consultant Pediatric Neurologist at Tawam Hospital, United Arab Emirates from May 2011 to August 2012 and associate clinical Professor at College of Medicine and Health Sciences, UAE University when he joined the American Center for Psychiatry and Neurology on September 2012. He is a member in the following societies: American Epilepsy Society, American Clinical Neurophysiology Society, European Pediatric Neurology Society, American Association of Neuromuscular & Electrodiagnostic Medicine and Asian & Oceanian Child Neurology Association and Infantile Seizure Society.

Dr. Saadeldin has also extensive experience in performing and interpreting electroencephalography. Dr. Saadeldin has published numerous papers in peer-reviewed international journals in the fields of pediatric neurology/epilepsy. Dr. Saadeldin presently works at the American Center for Psychiatry and Neurology in Dubai and Abu Dhabi, UAE.

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## Dr. Maha Elseed



Dr Maha Elseed; Assistant professor, University of Khartoum, MBBS University of Khartoum, Sudan. MRCPH, UK, 2003

Graduated from University of Khartoum in December 1994 and did her internship in Sudan and Saudi Arabia and then moved to UK and did her PLAB exam followed by MRCPCH parts I and II. She trained at Newcastle Upon Tyne Hospitals NHS Trust rotating between the RVI and Newcastle General Hospital and worked at Stockton -on-Tees and North Tyneside hospitals. She is practicing paediatrics with a special interest in paediatric neurology.

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# Dr. Inaam Noureldyme Mohamed





Dr Inaam Noureldyme Mohamed Assistant professor, University of Khartoum, MBBS University of Khartoum, Sudan. CMD, University of Khartoum 2005. Head of the neurology unit at Gafar Ibn Auf Specialized Hospital for Children.

Graduated from University of Khartoum in January 1994 and did her internship in Sudan. Joined the clinical MD program at University of Khartoum and graduated in 2005 she is practicing Pediatrics and Child Health with a special interest in pediatric neurology. With her colleague Dr. Ahlam Hamed and Dr. Maha Elseed they established the first paediatric epilepsy and neurology out patient-clinic in Khartoum. Head of the neurology unit at Gaffar Ibn Auf Specialized Hospital for Children.

She is a PET instructor and active member of the research council at Gaffar Ibn Auf hospital supervising of research thesis. She is an active member of the examination committee at the Sudan Medical specialization Board (SMSB) and has published a few papers in peer reviewed journals.

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## Dr Ahlam Abd Alrahman

Assistant professor, university of Khartoum



Graduated from the University of Khartoum and enrolled in the MD Program and was certified as paediatric consultant in 2003. She is the head of department of the paediatric unit at Soba Hospital and established the paediatric Neurology referral unit at Soba hospital. She is a PET instructor and is a lead member in the OSCE examination for both undergraduate and post graduate students. She is the lead paediatric consultant for clinical pharmacology and immunology subspecialty paediatric training.

## Dr. Nazim Haidar Abdel Aati DPH, MSc Child Health (Lond.) MRCPCH, CESR, CMI Cert.



Dr Nazim is Consultant Neurodevelopmental paediatrician with interest in Epilepsy and Neurodisability.

Dr Nazim graduated from Gezira University in 1996. He was elected as teaching assistant in the department of Community medicine after graduation. He completed his internship and then a postgraduate diploma in Public Health. He also worked as lecturer in community medicine in the International University of Africa and taught the first batch in the faculty of medicine in 1999/2000. He contributed to the development of the curriculum of community medicine in the International University of Africa based on Gezira model. He also volunteered to work and manage Malakal Children hospital in Southern Sudan during the Civil war; he was working closely with UNICEF and other National and International NGOs in 1998. He has been active charity volunteer since the age of 13 years. He is active member of the local school governing body in London. He contributes to National and International media in issues related to child health.

In UK he progressed with his paediatrics training and took several paediatrics posts in Lewishm, St Mary's and Imperial College NHS Foundation Trust and North East London Foundation Trust. He has been working as consultant community paediatrician since March 2013.Dr Nazim is on the GMC specialist register. He is a member of the Royal College of Paediatrics and Child Health. He is also a member of several British academies and association in the field of child health, childhood disability, community paediatrics and neurology. Dr Nazim has obtained MSc in community paediatrics from University of London. He has a certificate in management and leadership from the Charted management institute.

He has taken several lead roles during his work in community paediatrics in the UK. He is experienced in working in multi-agency settings.

He has been actively involved in the Community Child Health service improvement and development in North East London. The aim is to provide strategic direction for the Future of Community Paediatrics in North East London. The main goal is the development and implementation of a new model to integrate children's community services and child and adolescent mental health services. This is through:

- Oversee the development and implementation of a new integrated model.
- Monitor delivery of the project plan
- Ensure all risks are identified and managed.
- Actively contribute to delivery of the project objectives.

Dr Nazim in addition to his charity activities, he is keen to develop good relation between UK/Europe and Sudan in the field of Paediatrics and Child Health.

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## Dr. Ibrahim Ismael Adam Said



Ibrahim Ismael Adam Said (Ibrahim Adam M.D.)
Date and place of birth: Jerusalem - Palestine 1956

Education: MB.B.S. - University of Jordan

American board of psychiatry and Neurology - USA

Fellow in clinical Neurophysiology -

University of Medicine and Dentistry of New Jersey

Professions: Consultant in Neurology Chief of Medicine and Neurology Specialty Hospital, Amman - Jordan.

Note: Consultant In Neurology in well-recognized teaching institutes for physicians specializing programs approved by the Jordanian Medicine Council and Arab Medical Council, equal to a professor level at the medical schools and university hospital.

I regularly participate in the board examination certification Recognized by the Jordan Medical Council.

Consultant in Neurology (or other specialties given by the Jordan Medical Association).

Copy from the Jordan Medical Association included.

#### **Publications:**

\*Ataxia, Dementia and hypogonadotropism caused by Disorder Ubiquitination.

\*Ataxia, Amasita and Amenorrohea case study and review if the literature - submitted - Jordan medical Journal.

Associations:

\*Pathological characteristics of muscle disease in a private hospital, Amman - Jordan. Jordan medical journal (volume 38 - number 2 - Nov. 2004).

\*Associations between migraine and certain nutritional factors and the effect of diet on the alleviation of symptoms of the disease in a group of Jordanian patients.

Master degree - faculty of agriculture.

**Dr. Ibrahim Adam**. Co-supervisor.

\*Effect of reference Electrode position on sensory conduction studies.

Friday, Oct 4th 1996

AAEM annual meeting - USA.

# El Fatih Bashir ELMALIK MB BS, FRCSEd,, RCS(Surgical Neurology), FACS, Consultant Neurological

& Spinal Surgeon

El Ribat University Hospital, Royal Care International Hospital; Associate Professor, El Ribat University

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#### Qualifications

•	MBBS Faculty of Medicine, University of Khartoum	1982
•	FRCS The Royal College of Surgeons of Edinburgh	1990
•	FRCS(SN) The Intercollegiate Fellowship in Surgical Neurology	1994
•	FACS Fellowship of the American College of Surgeons	2005

#### Registration with Professional Bodies

- Specialist Register of the Sudan Medical Council
- Specialist Register of the GMC UK
- Registration with Qatar Supreme Health Council *Professional Membership*
- Sudanese Society of Neurological Sciences
- Sudanese Association of Neurosurgery
- Association of Sudanese Surgeons
- World Federation of Neurosurgical Societies
- Pan Arab Society of Neurosurgery
- Pan Arab Society of Neurological Sciences
- Pan Arab Spine Society
- African Federation of Neurosurgical Societies
- The Walter E Dandy Neurosurgical Society
- The Congress of Neurological Surgeons (CNS), USA
- American Association of Neurological Surgeons (AANS), USA
- Past member of the Society of British Neurological Surgeons (SBNS)
- · Past member of Swiss Spine Institute
- Past member of the International Spine Arthroplasty Society
- Past Fellow of the Royal Society of Medicine
- Past Member of World Federation of Neurology

#### Other Activities

- Examiner for the Intercollegiate MRCS in UK
- Member of WFNS Educational & Training Committee
- Member of the Editorial Board of the Pan Arab Neurosurgery Journal
- Member of International Editorial Panel World Neurosurgery Journal
- Founding member of the Pan Arab Society of Neurosurgery
- Founding member of Pan Arab Spine Society
- Founding member of Pan Arab Society of Trauma & Emergency Medicine
- Appointed member of the Supreme Council of Sudan Medical Specialization Board
- Past Examiner for FRCS, Royal College of Surgeons of Edinburgh
- Past Examiner for the Certification of Arab Board in Neurosurgery

Trained in Neurosurgery in Charing Cross Hospital and Newcastle General Hospital in UK Past Consultant Neurosurgeon at Charing Cross Hospital in London, Hamad Hospital in Doha-Qatar and Elribat University Hospital in Khartoum- Sudan.

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# Dr. Aisha Motwakil Bakhiet Gailani



MBBS 1993 Tanta University, Egypt MRCPsych, London 2005 CCT Psychiatry of Learning Disabilities, London 2009 DPM in Neuropsychiatry, Birmingham University, 2013

Consultant Psychiatrist, Taha Baashar Teaching Hospital

Assistant Professor, Department of Psychiatry, Faculty of Medicine, Khartoum University

Head Department of Psychiatry, Al Neelain University (2010-2014)

#### Training:

SpR in Learning Disability Psychiatry and child and Adolescent psychiatry,

1st May 2006 to 31st July 2009

Cambridge SpR training scheme,

Cambridge University, East Anglia

Staff Grade Psychiatrist- Hellesdon Hospital; from 4<sup>th</sup> August 2004 to 31st May 2006

SHO in in different specialities of Psychiatry, Norfolk Mental Health trust, Cambridge Training scheme, February 2001 to August 2004

Clinical Attachment in Old Age Psychiatry:

Julian Hospital, Norwich; From 14<sup>th</sup> November 2000 to 25<sup>th</sup> December 2000

Clinical Attachment in Psychiatry; Queen Elizabeth Hospital, King's Lynn; From

7th August 2000 to 12th October 2000

Clinical Attachment in General Adult & Community Psychiatry, Hellesdon Hospital, Norwich; From 25<sup>th</sup> August 1999 to 4<sup>th</sup> August 2000

Clinical Attachment in Psychiatry, St Clement's Hospital, Ipswich; From 1st February 1999 to 24th August 1999

Medical officer, Sudan; From 1st July 1995 to 31st March 1998.

Pre-registration House Officer Sudan from 1st July 1993 to 30th June 1995

E-mail:

# **ABSTRACTS**

#### APPROACH TO HEREDITARY ATAXIA/SPASTIC PARAPLEGIA IN CHILDHOOD

Mustafa A. M. Salish

#### Abstract

Spinocerebellar ataxias are characterized by disturbances of the body posture and coordination. They may result from one or any combination of dysfunction of the cerebellum and its associated systems, lesions in the spinal cord, or peripheral sensory loss. Other nervous system structures that are usually

affected in spinocerebellar ataxia include the basal ganglia and brainstem nuclei.

According to the mode of inheritance and gene in which causative mutations occur or chromosomal locus, spinocerebellar ataxias can be subdivided into autosomal dominant, autosomal recessive, X-linked, and mitochondrial. The underlying genetic defect remains unknown in about 40 % of suspected genetically determined ataxia cases. Nevertheless, the high incidence of consanguineous marriages in North Africa, including Sudan, and the Arabian Peninsula is reflected on the high prevalence of autosomal recessive (AR) disorders, in contrast to the situation in North America and Europe.

The current presentation outlines a diagnostic clinical and investigational algorithm for hereditary ataxia/spastic paraplegia in childhood.

Utilizing this algorithm and the power of family-based genetic studies combined with emerging DNA technology, new syndromes and diseases were identified. Those with gene identification included:

- 1. A new form of childhood-onset, autosomal recessive spinocerebellar ataxia and epilepsy (http://brain.oxfordjournals.org/cgi/content/full/130/7/1921) (http://www.ncbi.nlm.nih.gov/pubmed/24369382).
- 2. Spinocerebellar ataxia with axonal neuropathy (SCAN1; OMIM 607250; http://www.ncbi.nlm.nih.gov/books/NBK1105/).
- 3. Salih ataxia:

(OMIM #615705, http://omim.org/entry/615705)

(http://brain.oxfordjournals.org/content/133/8/2439.full.pdf+html)

#### (http://www.ncbi.nlm.nih.gov/pubmed/23728897).

4. A new form of childhood-onset autosomal recessive hereditary spastic paraplegia (SPG56) caused by a novel gene (CYP2U1) mutations (OMOM # 615030).

(http://omim.org/entry/615030)

(http://www.cell.com/AJHG/abstract/S0002-9297%2812%2900579-4).

These advances of pediatric neurogenetics helped in refashioning the prognosis and differential diagnosis of these diseases. It also made possible presymptomatic, prenatal, and pre-implantation genetic diagnoses for affected families.

# CHILD NEUROLOGY: DEVELOPING A MODEL OF CARE FOR RESOURCE POOR COUNTRIES BASED ON A NETWORKED APPROACH USED FOR DELIVERING SERVICES IN REMOTE AND RURAL SCOTLAND Alice Jollands.

The North of Scotland Child and Adolescent Neurology Network (NeSCANN) supports children with epilepsy, neurological and neurodisability conditions in an area covering almost a third of Britain. Although there are three urban centres, most of the region is rural and includes some of Britain's most remote communities. A model of 'multifaceted outreach' is utilised, incorporating joint consultations with local practitioners, education and continuous professional development with enhanced patient care through regular peer reviewand discussion. The network is predicated on the principle of providing care as close to the patient's home as possible through direct and 'indirect' clinical care. Increasing use of modern and cost effective communication technologies has and continues to enable the development of the network. Benefits of 'multifaceted outreach' include improved health outcomes, more efficient and consistent care and less use of in-patient services. In resource poor settings a networked approach may additionally overcome barriers to access where services may previously not have been available.

#### DIAGNOSTIC APPROACH TO THE FLOPPY INFANT SYNDROME

### Mustafa A. M. Salih

The complex of floppiness and hypotonia is a common neurologic symptom in infancy; and the floppy infant syndrome refers to an infant with generalized hypotonia presenting at birth or in early life. The diagnostic work up is often challenging, if a systematic clinical evaluation is not followed.

It has been a standard practice to decide first, whether the hypotonia is a manifestation of a motor unit disease or if it is due to a disorder of the central nervous system (CNS), or another system in the body.

The lower motor neuron, which composes the motor unit, has four subunits. These subunits consist of a motor neuron in the brainstem or ventral horn of the spinal cord and its axon, which together with other axons form the peripheral nerve; the neuromuscular junction; and the group of muscle fibers innervated by a single motor neuron.

Disorders of the CNS manifesting as floppy infant syndrome include cerebral dysgenesis/dysplasia, perinatal hypoxic/ischemic insult, kernicterus and intracranial hemorrhage; congenital infections; genetic syndromes and chromosomal abnormalities; and inherited metabolic disorders.

Spinal cord lesions, either congenital or following birth injury, can also manifest as floppy infant syndrome. Disorders of the motor unit associated with the floppy infant syndrome include diseases of the anterior horn cell, nerve, neuromuscular junction and muscle.

The diagnostic approach of the floppy infant syndrome should be guided by the clinical evaluation followed by pertinent neurophysiologic and laboratory tests.

# SPECTRUM OF PAROXYSMAL NON-EPILEPTIC DISORDERS IN CHILDREN AND MISDIAGNOSIS OF EPILEPSY AMONG THEM IN NEUROLOGY REFERRAL CLINICS IN KHARTOUM- SUDAN 2013

Dr. Maha A. Elseed, Aselma A. H. Mahdi, Rabih B. Rabih,

#### **ABSTRACT**

#### **Background:**

History taking from an eye witness of a paroxysmal event is of paramount significance in arriving at a correct diagnosis especially, that the examination is likely to be normal and investigations might not be helpful in achieving diagnosis. The first diagnostic step is to determine if the clinical presentation is compatible with epilepsy or with

other paroxysmal phenomena. Although this distinction often is easy to make clinically, certain conditions can be confused with seizures.

#### **Objectives:**

To identify the spectrum of paroxysmal non-epileptic disorders in children referred to two neurology referral clinics and to determine the rate of misdiagnosis of epilepsy among them.

#### Methodology:

In a descriptive cross-sectional prospective hospital based study, all children with a true diagnosis of paroxysmal non epileptic disorder were included in the study (63 patients); from the 1<sup>st</sup> of January to the 31<sup>st</sup> of December 2013. The referral was made to the paediatric epilepsy clinics at Soba University Hospital and Gafar Ibn Auf Specialized Children's Hospital.

#### Results:

Sixty three of children were given a final diagnosis of paroxysmal non epileptic disorder of childhood, with 60% of these misdiagnosed as epilepsy based on inadequate history and overestimation of electroencephalography findings. There was triggering factors in 63%, neurological premorbidities in 25%, abnormal neurological examination findings in 22% and abnormal EEG in 13% of total study population.

Syncope was the commonest cause of a non-epileptic event (30%) but there was a wide variety of other causes including parasomnias (24%), psychogenic nonepileptic attacks (14%), self-gratification phenomena (9.5%), febrile convulsions (4.8%), dystonia (4.8%), tics (3.2%), hyperekplexia (1.6%), infantile colic (1.6%), daydreaming (1.6%), paroxysmal kinesigenic choreoathetosis (1.6%), spasms nutans (1.6%) and paroxysmal vertigo (1.6%). Half of the patients were on antiepileptic drug therapy unnecessarily. Diagnosis reached by history in 97% of cases, other means include videotaping (28%), direct observation (24%), more than one electroencephalogram and electrocardiograms.

#### Conclusion:

In children with paroxysmal non epileptic disorder referred to neurology clinics, the diagnostic possibilities are numerous. Among them, syncopes predominated. Two thirds of them were misdiagnosed as epilepsy and most of these were on antiepileptic drug therapy.

#### RECOMMENDATIONS FOR THE MANAGEMENT OF NEONATAL AND INFANTILE SEIZURES

#### Jo Wilmshurst

Guidelines exist for children with seizures which are of onset in the neonatal and infantile age range. These have devolved to more expert opinion, and recommendations, since evidence based data is lacking. Major understanding relating to neonatal seizures support the concept that abnormal electrical activity has adverse effects on brain maturation, and that ideally all abnormal activity should be closely monitored for, using continuous screening, and responded to acutely. Unfortunately optimal antiepileptic drugs, and other therapeutic interventions, are lacking, as well as adequate resources in most settings. Research continues to target both the effects of seizures in this group and to examine alternative interventions. In the infantile age group one of the greatest challenges is the misdiagnosis of seizures when events are infact non-epileptic paroxysms. Good clinical assessment and witnessed descriptions are essential. Whilst seizures in the infantile age group are of greatest prevalence of all ages, many of the seizure types represent rare entities for specific syndromes. The development of orphan drugs and registries to monitor the efficacy of these syndromes remains an important tool to develop better management, and as such, outcomes for these children. The major epilepsy affecting the infantile age group is epileptic spasms, various interventions are recommended and this disorder has been studied extensively

## ACUTE DISSEMINATED ENCEPHALOMYELITIS (ADEM) IN A FOUR YEAR SUDANESE GIRL.

#### Satti A. Satti

#### Abstract

Acute Disseminated Encephalomyelitis (ADEM) is an acute demyelinating disease, of autoimmune etiology, most commonly affects children. It is a white matter inflammatory disease. It usually follows a viral infection, a nonspecific upper respiratory infection or vaccination. ADEM is a predominantly a disease of children and in particular infants. Most cases have favorable outcome, but few are severe or fatal. Diagnosis carries important therapeutic and prognostic implications.

MRI is the neuroimaging study of choice for establishing the diagnosis and for following the course of the disease. Multiple sclerosis is the main differential diagnosis. Rarely there is what is called ADEM-like presentation. Most children respond well to corticosteroids.

Here we present a four year old girl admitted with ADEM with typical MRI changes and favorable prognosis after aggressive management in our hospital.

#### **AUTISM IN TUBEROUS SCLEROSIS COMPLEX: A CASE REPORT**

Isra k. A. Ahmed

#### Abstract

A 10 year old girl was presented to the referred clinic, complaining of recurrent attacks of convulsions since the neonatal period.

Examination revealed that the child has adenoma sebaceum on the face with butterfly distribution, hypopigmented macules on both sides of the trunk, periungual fibroma on the right ring finger. CT scan of the head showed right frontal lobe and periventricular calcifications, and a diagnosis of Tuberous Sclerosis was made. Association of autistic behaviors and severe degree of mental retardation was noticed in the child and raised the need for multi-disciplinary approach.

# CLINICAL PROFILE OF PEDIATRIC NEUROLOGICAL DISORDERS AS SEEN IN OUTPATIENT CLINIC IN KHARTOUM, SUDAN

Inaam. N. Mohammed, Maha E, Ahlam A. Hamed.

#### Background

Neurological disorders account for more than 20% of the world's disease burden with a greater majority of people affected living in Africa. Due to chronicity, late presentation, unavailability of certain diagnostic facilities as well as manpower; neurology services are very challenging with significant increase in morbidity and mortality. This talk aims to demonstrate the pattern of pediatric neurological disorders, reflecting the challenges of investigation and management and expressing the future needs.

### **Results**

A total of 6019 patients were enrolled in the study. Their age was between 3months and 18 years and a male to female ratio was 2:1. The majority of patients were from Khartoum State; however there are considerable numbers of patients coming from all over Sudan. The majority of patients had epilepsy and other neurodisabilities including learning difficulties. That amounted to 52.8%, followed by Cerebral Palsy (19.1%), Congenital Anomalies of the Central Nervous System (6.2%), Neuromuscular Disorders (3.2%), Stroke (2.4%), Ataxia and Movement disorders (1.9%) and Syndromes (1.2%). Demyelinating disorders, Headache, Neurodegenerative, Mitochondrial, Metabolic, Hereditary Sensory and Motor Neuropathy, Behavioral disorders, in addition to other rare and unresolved conditions accounted for the other 14.4%.

**Conclusion and recommendations**: Neurological disorders constitute a major cause of chronic morbidity in pediatric age group. Appropriate allocation and distribution of relevant resources, and other recommendations will be addressed in this presentation.

#### **NEUROCOGNITIVE DEVELOPMENT IN PAEDIATRIC EPILEPSY**

#### Patrick Van Bogaert

Cognitive deficits are highly prevalent in children with epilepsy, ranging from 25 to 50% depending of age groups (1-3). In addition to onset of epilepsy in infancy, other risk factors for cognitive deficits are resistance to anti-epileptic drugs (AED) and symptomatic etiology. The origin of the cognitive deficits is often multifactorial, and the challenge for the clinician is to identify the respective roles of the underlying etiology, the possible side effects of AED, and the epileptic activity (clinical seizures as well as interictal epileptiform discharges, IED). The role of epileptic activity is recognized in epileptic encephalopathies. Indeed, epileptic encephalopathy embodies the notion that the epileptic activity itself may contribute to severe cognitive and behavioral impairments above and beyond what might be expected from the underlying pathology alone, and that these can worsen over time (4). A longitudinal study performed in a cohort of patients with epilepsy onset before age 3 has confirmed progressive adaptive behavior decline in epileptic encephalopathies starting in infancy, i.e. West syndrome, Dravet syndrome, and early-onset Lennox-Gastaut syndrome (5). In some syndromes like Dravet syndrome, it is probably the repetition of seizures that contributes to cognitive decline, as IED are not abundant or even absent in the first stages of the disease. One study suggests that it is the occurrence of myoclonic seizures and absences but not convulsive seizures that are associated to cognitive decline (6). In West syndrome, it is probably the interictal EEG abnormalities, i.e. the

hypsarrhythmic pattern, which is detrimental for cognitive development. Thus, early control of spams is essential for cognitive outcome at least in West syndrome without underlying etiology identified (7). In epileptic encephalopathies with continuous spike-waves during slow-wave sleep (CSWS), clinical and imaging studies evidence that interictal epileptic activity during sleep plays a major role in cognitive deterioration observed in these patients when awake(8). Finally, first data of epilepsy surgery in children support the positive effect of surgery on cognition when performed early in the course of the disease (9).

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#### RECOGNIZING COMMON PEDIATRIC EPILEPSY SYNDROMES

Karen L. Skjei

#### Abstract

Epilepsy is a common disorder, occurring in approximately 1% of people, with peak onset in infancy and childhood. It can have severe consequences in the developing brain, including permanent cognitive, psychosocial, and motor delays. The critical factor in determining treatment and prognosis is recognizing the specific epilepsy syndrome. In this lecture we will review the presentation of common pediatric epilepsy syndrome, taking into account the factors that aid in the diagnosis of these syndromes, including age of onset, seizure type(s), medical history; developmental/academic history; family history; physical examination and clinical course. Appropriate evaluation and treatment for the syndromes will also be reviewed.

#### SEIZURE SEMIOLOGY IN INFANTS/CHILDREN AND COMMON SEIZURE MIMICS

Karen L. Skjei

#### **Abstract**

Seizures in infants and young children can be subtle and difficult to recognize. There are numerous seizure mimics that occur in the pediatric age group that can be misdiagnosed as seizures. These include Sandifer syndrome, complex breath holding spells, stereotypies, and many others. In this lecture we will review a few video examples of subtle seizures in infants and children, and then focus the majority of the talk on recognizing common seizure mimics.

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#### **SEIZURES IN SPECIAL GROUPS**

Khalid O. Ibrahim

#### **Abstract**

The incidence of learning difficulties in children is about 0.3-0.8% and 20-30% of them may have epilepsy. Children with epilepsy have higher incidence of learning difficulties (35%). There is an increased incidence of epilepsy in cerebral palsy. Diagnosing seizures and describing their semiology can be quite challenging in children with learning disabilities and CP. There are a lot of seizure mimics which can be observed in such group of children, making diagnosis even more difficult. A review of the topic including presentation, acute management including approach to investigation, selection of medication and identification of triggers will be discussed in this talk.

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#### APPROACH TO STATUS EPILEPTICUS IN RESOURCE POOR COUNTRIES

#### Jo Wilmshurst

Status epilepticus is defined as generalised convulsions lasting 30 minutes or more, beyond this the risk of brain damage is established. The greater the time taken to control seizures, the greater the secondary sequelae. the underlying aetiologies influence the ability to control seizures and the neurological outcome further. In the developed world various forms of brain monitoring are increasingly utilised to attain optimal seizure control. this has lead to more targeted care for these patients. Treatment of status epilepticus can be divided into pre-hospital treatment, emergency ward treatment, in-hospital treatment and anaesthesia (intensive care). Numerous recommendations exist for the management of status but none are evidence based beyond the standard first line therapy with benzodiazepines. These interventions are driven by the capacity of the facilities that the children present to. Newer generation agents (e.g. intravenous levetiracetam) are increasingly replacing the previously used standard agents (e.g. phenytoin, phenobarbitone). Most facilities throughout the world do not have access to brain monitoring, or to the newer agents, let alone the most basic of resuscitation equipment (e.g. saturation monitors, syringe drivers). as a result some of the most needy and complex children are managed in settings with the least capacity to care for them. Various initiatives are underway in such resource poor settings to optimise the management of status epilepticus in the most effective way.

#### **JUVENILE MYOCLONIC EPILEPSY**

#### **Tahir Obeid**

Juvenile myoclonic epilepsy is commonest form of idiopathic epilepsy which is usually missed diagnosed. Myoclonic morning jerking is the hallmark of the syndrome with generalized tonic clonic convulsion occurring in most, but absences are less frequent. The authors described their published experiences on this syndrome which includes: Clinical, EEG findings, some of genetic aspects and factors that lead to diagnostic errors. The current literature on the syndrome and some highlights on progressive myoclonic epilepsy which one of the commonest differential diagnoses are also presented.

#### **EPIDEMIOLOGY OF EPILEPSY AMONG SCHOOL CHILDREN IN KHARTOUM STATE-2014**

Ahlam A. Hamed, Maha E., Inaam. N. Mohammed

#### **Abstract**

The prevalence of epilepsy is high in tropical countries, particularly in Africa where it varies between 10 and 55 per 1000, with an estimated mean prevalence of 15 per 1000. Younis YO in 1978 described selected findings of a survey of epilepsy among the school population in Khartoum Province. A prevalence rate of epilepsy of 0.9 per 1000 was estimated. This might be an underestimate as only 39.5% of the school aged children were enrolled in schools at that time. Other African countries reported a prevalence ranging between 7.3/1000 and 41/1000. Very little is known about the situation of childhood epilepsy in Sudan, as far as published literature. The main aim of this study is to measure the prevalence of epilepsy among school children in Khartoum State, classify the types of epilepsy, identify risk factors, identify learning difficulties and measure the outcome within one year in form of compliance, side effects of the AEDs, degree of control of epilepsy and school performance. This is an analytical-population based, cross sectional study. Conducted at Khartoum State, which is the capital of Sudan. The study included Students in the basic schools whose age range from 6- 14 years. This is a multistage sampling; as it covers 4 localities out of 7 in which the schools were selected using Simple Random Sample by using Random digit table. The sample frame consisted of 808624 public school students and 194613 private schools students. The sample

was distributed to cover both males and females pupils and included private as well as governmental Schools. The total number of schools visited was 210 representing 10% of the total number of schools in Khartoum State. The prevalence of epilepsy and the types of seizures in this age group will be addressed in this presentation.

### Paediatric neurology service in Sudan; Current situation and future challenges.

Maha A. Elseed, Inaam. N. Mohammed, Ahlam A. Hamed

#### **Abstract**

Children with neurological problems were historically seen in adult neurology clinics by our dedicated teachers and professors from 1950s. The amalgamation with adult services, excellent as it was, denies this group the specialized care they deserve.

The service was then extended by establishing a specialized child neurology clinic at Saad Abu el Ella hospital followed by Soba clinic and Gafar Ibn Ouf hospital clinic Khartoum. There is a separate service provision in Medani. That is the only clinic in the states. These clinics serve the whole of Sudan. Gafar Ibn Ouf hospital serves as the main inpatient tertiary referral centre in all paediatric specialties including a dedicated paediatric neurology ward whereby acute services are delivered.

The numbers of patients are exponentially increasing and the average number seen per clinic is now up to 60 patients referred from all over Sudan. We are also now seeing patients referred from neighboring countries as well such as Chad, Eretria and South Sudan where facilities for neurological investigations are limited. The total number of paediatric neurology patients seen over the last 8 years was 9600 Patient at Saad Abu El Ella hospital alone.

The paediatric neurology load is apparently on the rise necessitating the provision of adequate supportive and multidisciplinary team services. This paper highlights the current situation, the challenges encountered and the future goals. The human resources as well as the availability of affordable necessary investigations and essential drug provision are our main challenges. There is a dire need for team and capacity building, research implementation and organization of outreach sces.

Competing interests: None

# SPINAL CORD SCHISTOSOMIASIS; A TREATABLE CAUSE OF CHILDHOOD PARALYSIS IN SUDAN El Fatih B. El Malik

#### **ABSTRACT**

#### INTRODUCTION:

Schistosomiasis is a prevalent parasitic infection worldwide where 600 million people are at risk, and over 200 million are infected. Hepatic and urinary systems are the main targets but CNS involvement is considered a rare manifestation of the disease. We report a series of 51 consecutive cases of spinal cord schistosomiasis (SCS) from Sudan, involving mainly the conus medullaris region. We aim to raise awareness among health care professionals about the existence of Neuroschistosomiasis. With the ever expanding worldwide network of travel and transport, visitors to tropical areas are at risk of encountering conditions endemic in those parts of the world. This presentation emphasizes the importance of bearing a high index of suspicion when dealing with relevant cases. It proposes a simplified scheme for diagnosis and treatment of SCS.

#### **METHODS:**

This is a report of a series of 51 consecutive patients with SCS treated over a period of 7 years, between January 2007 and December 2013. There were 32 males and 19 females with age range from 5 years to 65 years, mean 15.9. Most of the patients - 45 cases (88%) - presented with acute or subacute paralysis of the lower limbs and sphincter disturbance. The remaining 6 cases presented with unilateral lower limb radiculopathy and sphincter disturbance. In keeping with reports in the literature, MR Imaging was positive in all the patients and showed diffuse hyperintensity on T2WI and expansion of the distal segment of the spinal cord on T1WI with variable enhancement patterns after contrast injection. These will be highlighted with case presentations. In our management protocol, a patient with positive clinical and MRI features would be given treatment promptly in form of Praziquantel and Dexamethasone while undergoing the rest of the investigations. The latter includes serological testing by ELISA. Regular interval clinical and radiological follow up was done. RESULTS:

46 cases (90%) made complete or near complete neurological recovery with corresponding remarkable improvement on follow up MR imaging within 6 weeks of commencing treatment while 6 patients who presented late remained paralyzed. Serology tests were performed for 27 patients and results were reported as strongly positive for active Schistosomiasis. Two patients had had complete paralysis for a long time and did not respond to medical

treatment hence underwent surgical intervention. In both cases histopathological studies of the specimens revealed schistosomal eggs with granulomatous reaction of the spinal cord.

- CONCLUSIONS:
  - A high index of suspicion for SCS should be borne in mind in relevant cases, in Schistosomiasis endemic regions or for those who have recently been to these regions.
  - Patients, mainly children and teenagers, who present with neurological disorders involving the sphincters and lower limbs, should undergo spinal cord MRI examination including the conus region. Characteristic MRI abnormalities noted in this group of patients will be highlighted that should propose the diagnosis of Schistosomiasis.
  - Lack of history of exposure to the disease and negative general laboratory test results do not rule out the diagnosis.
  - Blood serological test for Schistosomiasis carry high sensitivity and specificity that obviates the need for CSF analysis.
  - Prompt commencement of treatment with anti-bilharzia drugs, namely Praziquantel, and steroids can lead to
    neurological recovery while delay in the diagnosis and treatment and surgical insult to the oedematous
    conus region based on the erroneous diagnosis of spinal cord tumour may result in irreversible neurological
    damage that could involve permanent lifelong lower limb weakness, sphincter disturbance and impotence.

#### PAIN IN THE NEURODISABLE CHILD: "ADDING INSULT TO INJURY"

#### Mohamed E. Al-Malik

Pain is common during childhood and become more common and more frequent and added burden in the neurodisabled children. An epidemiologic survey showed that Neurodevelopmental disabilities is common affecting 1% to 3% of children 30% of them experience chronic pain. It is so important and common problem which is often overlooked and passed un-noticed, though found to be very much associated to participation, function, and health-related quality of life in these children and their families.

The complex nature of the neurodisability made the Identification and management to be so challenging to the Paediatricians and the neurologist.

I hope by presenting this review I will be able make the audience more aware and oriented, through the following objectives:

- Throw some light on the epidemiology of Pain in Neurodisabled child
- Be aware of the nature of pain and its significance
- To know the Common Causes of pain in Neurodisabled child
- How to evaluate the pain in Neurodisabled Child
- To be aware of the available management modalities

# EPILEPTIC ENCEPHALOPATHIES IN EARLY INFANCY WITH SUPPRESSION-BURSTS EEG PATTERN IN SAUDI CHILDREN FROM THE EASTERN PROVINCE OF KSA

#### **Elsayed A. Mohamed**

#### Abstract

**Purpose**: Epileptic encephalopathy in early infancy with suppression bursts (SB) EEG pattern comprises two distinct epileptic syndromes, early infantile epileptic encephalopathy (EIEE, or Ohtahara syndrome) and early myoclonic encephalopathy (EME).

The aim to draw attention on these debilitating early infantile epileptic encephalopathies, so that can be early recognized and appropriately treated.

**Methods:** Charts records of 8 children (3 males and 5 females) admitted to child neurology service between September 1999 and August 2012 were reviewed. Digital- Video EEG was performed in 6 patients and paper EEG in 2. Neuroimaging and metabolic workup was done for all patients.

**Results:** Five cases fulfill criteria for early infantile epileptic encephalopathy (EIEE) and 3 cases with early myoclonic encephalopathy (EME). The mean age at the time of onset of seizures was12 days. EEG in all patients showed suppression-burst (SB) patterns. In two cases evolved into hypsarrthymia.

Seizure semiology composed of tonic spasms in some cases, and generalized or partial patterns in others.MRI brain was abnormal in 5 cases (3 scans revealed cortical atrophy, 1 hemimegaloncephaly, and 1 white mater demylination).

Metabolic workup was abnormal in 3 cases (high CSF/plasma glycine ratio in Non-Ketotic hyperglycinemia, increased serum VLCFAs in Zellweger syndrome and high serum lactate in child with Cytochrome C Oxidase deficiency)

Anti-convulsant therapy was successful initially in one patient, but later relapsed, another child referred for hemispherectomy, and the rest of patients (6 cases) various combinations of AED therapy was tried and has failed in controlling their seizures and halting the deterioration of psychomotor development.

Unfortunately no genetic testing was done for the cryptogenic cases.

**Conclusion:** Malignant Epileptic Encephalopathies in Early Infancy needs to be recognized early, thoroughly investigated to determine the underlying etiology and aggressively treated to alter their poor prognosis

#### **Challenges of Practicing Learning Disability Psychiatry in Sudan**

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#### Abstract

Many factors contribute to increased rates of disabled people such as, poverty, consanguinity, iodine deficiency in Western Sudan as well as poor medical care. According to 2008 census there were 1,463,034 people with disabilities; this constitutes 4.8% of the population. The highest rate of disability was amongst the category of 5 to 14 years of age (14.9%). However there were no specific statistic figures for intellectual disabilities (IDs). The Health expenditure is 1.6 % of the country's budget. The expenditure on mental health is unknown.

A lot of challenges face provision of specialized care for Sudanese children with IDs. The Sudanese community is a reserved community with a very close social fabric and strong religious believes. Stigma against disabled people and mental illnesses in general, is still a great obstacle for accessing services. Sudanese patients prefer seeking traditional healing as it is more accepted culturally than going to see a psychiatrist. However, in some Sudanese communities a disabled child can be seen as a blessing. This can also expose them to exploitation, as they can be used as a source of money, when people come to them seeking blessings or healing of their ill patients. This can hold families from seeking health care or education for disabled children as they get used to their disability as a source of income for the family.

Other obstacles to establish specialized service for people with IDs is the lack of real statistic, and the government and decision makers do not give priority to services for the disabled. However, in 2013, the Ministry of Education took critical steps to give children with disabilities the chance to receive a quality education. In reality this has not been applied yet. There are some individual efforts to provide services for people with disabilities, especially those with intellectual disabilities. Most of the specialized schools for children with (IDs) are owned and run by parents of disabled children. These centres offer life span service for children and adults with LD, being looked after in the same building using same toilets and other facilities. This unsuitable environment exposes these children to different types of abuse.

There is no governmental supervisory body to govern these schools and there are no protocols or guidelines to guide practice of these centres. Training for staff is not done in a proper way as it is patchy and does not follow evidence based practice. Most of these centres are commercial by nature and too expensive for poor families to afford. Furthermore, the staff is poorly paid as well as often poorly trained.

There are real diagnostic issues of learning disabilities as there is no clear referral pathway and no proper multidisciplinary team work. It is worth mentioning that despite scarcity of services for disabled children, most of them are clustered in the capital; Khartoum leaving other parts of the country with no specialized services for the disabled.

This presentation will highlight some of the challenges as well as the individual efforts that have improved the lives of children with IDs. Giving a glimpse of hope for a better future for these children and their families.

In the absence of significant research (except in a minority of areas), the evidence is derived from descriptive studies and clinical reviews. This guideline represents the best evidence available and it provides a source document for both commissioners and service providers in the assessment and management of this stigmatised and neglected group of patients.

PEDIATRIC CEREBRAL PALSY IN AFRICA: WHERE ARE WE?

Kirsty A. Donald

#### **Abstract**

Cerebral palsy is the most common cause of physical disability in children worldwide. However, little is reported on this condition in the African context. Doctors from 22 countries in Africa, and representatives from a further 5

countries outside Africa, met to discuss the challenges in the evaluation and management of children with cerebral palsy in Africa and to propose service needs and further research. Basic care is limited by the poor availability of diagnostic facilities or medical personnel with experience and expertise in managing cerebral palsy, exacerbated by lack of available interventions such as medications, surgical procedures, or even regular therapy input. Relevant guidelines are lacking. In order to guide services for children with existing disabilities, to effectively target the main etiologies and to develop preventive strategies for the continent, research priorities must include multicenter collaborative studies looking at the prevalence, risk factors, and treatment of cerebral palsy.

# TRADITIONAL AND SPIRITUAL MEDICINE AMONG SUDANESE CHILDREN WITH EPILEPSY Inaam N. Mohammed, Haydar E Babikir

#### **ABSTRACT**

This cross sectional hospital based study, carried out simultaneously in Khartoum and in Wad Madani, Al Gezira State, aimed to study the impact of spiritual beliefs on explanation of the epilepsy etiology and the choices and methods of spiritual and traditional medicine used in the management of epilepsy in Sudan. The study included 180 care givers of whom 165 (91.7%) were mothers. Their ages ranged between 30-40 years. The majority (88.8%) were educated and 60 (33.3%) of them live in rural areas. Fifty eight (32.2%) attributed epilepsy to supernatural causes while 41 (22.8%) and 90 (50%) thought that epilepsy is an untreatable and contagious disorder, respectively. Traditional and spiritual medicine for the treatment of epilepsy was used by 70.5%. The common spiritual technique used was incantations (45.6%), spitting cure (37.2%) and ritual incensing (36.7%). Herbs, black cumin (*Nigella sativa*), honey and olive oil were mentioned among others as a traditional treatment for epilepsy. About two fifth (42.5%) started traditional or spiritual treatment before seeking any medical advice. Nevertheless, only 2.4% stopped the medical treatment as advised by the traditional healer. Fifty five (43.3%) thought that spiritual and/ or traditional treatment were effective in the management of epilepsy, 60(47.2%) found no difference while 12(9.45) got worse. The majority of patients with epilepsy, although on medical treatment, used traditional and spiritual methods as well. Traditional and spiritual healers may be involved positively in the management of epilepsy and extensive public educational programs are needed.

#### COMMUNITY CHILD HEALTH SERVICE IMPROVEMENT AND DEVELOPMENT IN SUDAN

Nazim Abdel Aati,

#### **Abstract**

Introduction:

A visiting team composed of two Speech and Language Therapists and one community paediatrician had visited Sudan with the aim of raising the awareness about managing and rehabilitating children with physical, neurodevelopmental and multisensory impairment. The team has worked with local Sudanese professionals and identified several needs in community child health.

Method:

Information was collected from visits to universities, clinics, orphanages, rehabilitation homes and other institutes. Information was collected through focus group discussions, direct interviews of professionals and parents as well as from clinics.

Results:

A total of 52 families have been interviewed and their children have been assessed. There is clear lack of awareness, understanding of the nature of several neuro-disabilities and neurodevelopmental disorders and their management.

The need for education, training, research, service improvement and development in community child health, neurodevelopment, multisensory impairment and neuro-disabilities have become very clear.

Conclusion:

All parties including local charities, UK visiting professionals, Sudanese professionals and parents agreed the importance for service improvement and development as well as empowering local professionals through education, training and research.

The second mission from UK will include senior therapists and senior community paediatrician. The aim of the visit is to explore the possibility of establishing a centre of excellence in Child Development and Community Child Health. The team will also explore the possibilities of running both undergraduate and postgraduate programmes in SALT and Occupational therapy in Sudan. The mission participants will deliver their views in the International Child

Neurology Association (ICNA) Conference that will be held in Khartoum in the period from 28 – 30 January 2015. The session will be in a workshop for targeted audiences.

### ATAXIA DEMENTIA, AND HYPOGONADOTROPISM CAUSED BY DISORDERED UBIQUITINATION

#### Ibrahim Adam

#### Abstract:

### Background:

The combination of ataxia, and hypogonadotropism was first described more than a century ago, but its genetic basis has remained elusive.

#### Methods:

We performed whole-exome sequencing in a patient with ataxia and hypogonadotropic hypogonadism, followed by targeted sequencing of candidate genes in similarly affected patients. Neurologic and reproductive endocrine phenotype were characterized in detail. The effects of sequence variants and presence of an epistatic interaction were tested in a zebra fish model.

#### Results:

Digenic homozygous mutations in RNF2016 and OTUD4, which encode a ubiquitin E3 ligase and deubiquitinase, respectively, were found in three affected siblings in a consanguineous family. Additional screening identified compound heterozygous truncating mutations in RNF216 in an unrelated patient and single heterozygous deleterious mutations in four other patients. Knockdown of mf216 or otud4 in zebra fish embryos induced defects in the eye, optic tectum, and cerebellum; combinational suppression of both genes exacerbated these phenotypes, which were rescued by nonmutant, but not mutant, human RNF2016 and OTUD4 messenger RNA. All patients had progressive Ataxia and dementia. Neuronal loss was observed in cerebellar pathways and the hippocampus; surviving hippocampal neurons contained ubiquitin-immunoreactive intra-nuclear inclusions. Defects were detected at the hypothalamic and pituitary levels of the reproductive endocrine axis.

#### Conclusion:

The syndrome of hypogonadotropic hypogonadism, ataxia, and dementia can be caused by inactivating mutations in RNF216 or by the combination of mutations in RNF2016 and OTUD4. These finding link disordered ubiquitination to neurodegeneration and reproductive dysfunction and highlight the power of whole-exome sequencing in combination with functional studies to unveil genetic interaction that cause disease (funded by the National Institutes of Health and others)

In recent years, we have seen great advances in the elucidation of genetic causes of cerebellar ataxia, with newly identified genes regulating a wide spectrum of cellular functions, including intracellular signaling, tau regulation and mitochondrial function. However, a genetic defect cannot be found in approximately 40% of patients with ataxia including those in whom ataxia is associated with reproductive endocrine failure, a syndrome first reported by Gordon Holmes in 1908. Most patients with this syndrome have a hypogonadotropic condition, with defective secretion of gonadotropins by the pituitary gland. Strikingly, genes associated with ataxia have little functional overlap with genes associated with, hypogonadotropic, hypogonadotropism, which encode proteins involved in the biologic function of the neurons that secrete gonadotropin releasing hormone

A decade ago, we described a consanguineous family with a syndrome of cerebellar ataxia, dementia and hypogonadotropic hypogonadotropism, here we report the results of whole-exome and targeted sequencing performed to identify mutations that underlie the syndrome in this kindred and in unrelated patients



## POSTERS PRESENTATIONS

#### DYSTONIA DIAGNOSIS: ARE WE STILL ON THE CROOKED, TWISTY ROAD?

#### Maha A. Elseed

Dystonia is a movement disorder that involves sustained twisting of muscles that can be life threatening and alarming especially if it involves the laryngeal muscles causing stridor and upper airway obstruction. It may also lead to myoglobinuria and renal failure. Status dystonicus is a life threatening condition that requires an immediate management with muscle relaxants and benzodiazepines. Dystonia muscularum deformans is a severely disabling condition that severely affects such a quality of life of the patient and family alike. Feeding, daily cares and mobility remain pose challenging issues for the neurologist.

The causes are myriad but with the advent of new sequencing technologies, there has been a step change in the pace of discovery of dystonia genetics. Four genes have been linked to primary dystonia C1Z1, ANO3, TUBB4A and GNAL <sup>1</sup>. PRRT2 has been identified as a cause for paroxysmal kinesogenic dystonia as well as others linked to more complicated forms <sup>1</sup>.

We hereby present a 2 year old Sudanese boy who presented with early onset dystonia. He is an only child born to consanguineous parents by a normal full term vaginal delivery and had no neonatal concerns. Following a viral febrile illness at the age of 9 months, he started to develop severe generalized dystonia and self-mutilating behavior associated with regression in all his previously acquired milestones. Clinical examination revealed a normal head circumference, no dysmorphic features or neurocutaneous stigmata, an opisthotonus posturing with severe generalized dystonia.

His investigations revealed a normal brain MRI and a normal uric acid level. He had a poor response to Baclofen, Benzodiazepines, Chloral Hydrate and Anticholinergic medications. His life and his family's became miserable with prolonged hospital admissions to receive Intravenous Midazolam infusions that were the only relief to his condition. Comparative Genomic Hybridization (CGH) was done in a blood sample that was sent to the National Genetics Reference lab in Wessex, using a 4X180 K oligoarray platform that revealed a submicroscopic deletion in chromosome 1q31.3. That anomaly is suggestive of Nuclear Factor IA (NFIA) Haploin sufficiency which is linked to CNS malformation syndromes and urinary tract defects<sup>2</sup>. Five individuals were described with thin, hypoplastic corpus callosum, hydrocephalus and venticulomegaly, Chiari I malformation, tethered cord and vesicoureteric reflux. Our child depicted here had none of the above problems but had a disabling dystonia.

The question remains: Will genetic screening in our Sudanese dystonia patients with our high consanguinity rates and our immense intertribal marriage offer new genetic information and will this information have an effect on the life of these children and their families in the for seeable future?

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## Neuronal Cortical Migration Disorder Associated with Epilepsy in Sudanese Male Twins.

#### Haydar E. Babikir1, Mohmmed Salah Magzoub2, Anas O. Hamdoun3

Epilepsy is the most common neurological disorder affecting young people. The aetiologies are multiple and most cases are sporadic. However, genetics malformations have important role. Disturbances of neuroblast migration and consequently abnormal development of the human cortex are recognized as significant causes of mental retardation, symptomatic epilepsy, and congenital neurologic deficits with abnormal neurological development in children. These malformations may be restricted to the brain or may be one component of a generalized malformation syndrome. This review will discuss two male twins with cortical malformation and epileptic seizures failure to thrive, microcephaly and global developmental delay. The classical facies of Miller-Dieker syndrome are not present. The family history suggested a hereditary disorder of XL type.

**Key words:** epilepsy, child, cortical migratory disorders, Miller-Dieker syndrome, genetic inheritance twins Sudan.

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# Central Pontine Myelinolysis (CPM) following Burn Injury in a Sudanese Girl (Poster) Haydar E Babikir MD

Central pontine myelinolysis (CPM) Is a unique clinical entity. Adams et al in 1958, described that patients who suffered from alcoholism or malnutrition developed spastic quadriplegia, pseudobulbar palsy, and varying degrees of encephalopathy or coma from acute, non-inflammatory demyelination that centered within the basis pontis. Contemporary physicians recognize that CPM occurs inconsistently as a complication of severe and prolonged

Contemporary physicians recognize that CPM occurs inconsistently as a complication of severe and prolonged hyponatremia, particularly when corrected too rapidly. Standard of care requires judicious treatment of electrolyte disturbances to reduce the incidence of osmotic myelinolysis.

We are presenting here a case of CPM in a Sudanese girl presented with key features of CPM following scald burn. **Key words:** Central pontine myelinolysis, burn, Sudanese girl

## Aicardi-Goutières Syndrome (Poster)

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Background: Aicardi-Goutières Syndrome (AGS) was first described in 1984. To date, the literature reports 69 cases throughout the world. AGS most frequently inherited in an autosomal recessive manner; in a few instances the disease can result from *de novo* autosomal dominant mutation of *TREX1* or *ADAR*. It is characterized by encephalopathy, hepatosplenomegaly, skin lesions and calcification of the basal ganglia and a white matter changes. TORCH congenital infections are the most common conditions in the differential diagnosis and the most important to rule out because misdiagnosis would result in erroneous counseling as to risk of recurrence. We feel that AGS and other inherited causes of intracranial calcification are common in Sudan

