

# Education in Child Neurology: The Role of the International Child Neurology Association (ICNA)

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## Abstract

Recent progress in pediatric neurosciences has greatly increased the divide between the possibilities for diagnosis and intervention among developed countries and resource-poor countries, where child neurologists suffer from the lack of adequate training, the absence of a network with professionals around the world, and the shortage of infrastructure. The International Child Neurology Association (ICNA) is the only child neurology association that can deal with these important issues and promote the reduction of this gap. In this article, the author reviews the role played by ICNA in the past 2 decades in supporting education worldwide, in offering teaching seminars and visits by senior members, and in addressing the needs of the global community of child neurologists. The challenges and success of ICNA in the promotion of educational resources and recommendations for the future are discussed.

## Keywords

training, International Child Neurology Association, ICNA, education

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Progress in pediatric neurosciences is proceeding rapidly, and we are entering an era in which technologies will allow a greater knowledge of normal and abnormal brain developments. Because of increased diagnostic abilities, early recognition of even subtle brain abnormalities is now possible, thus allowing early intervention. Many children in certain areas of the world do not have the chance to benefit from this progress because of the shortage of well-trained child neurologists as well as equipped centers and general infrastructure. The advances made during the past years and the growing necessity for advanced technology to diagnose central nervous system disorders have greatly increased the divide between the possibilities for diagnosis and intervention between developed countries and developing ones. Furthermore, child neurologists from developing countries suffer from the lack of a network that can provide continuous education and updates. Thus, education has become an ever important issue. The International Child Neurology Association (ICNA) is the only organization that can deal with these important issues and promote the reduction of this gap.<sup>1</sup>

In this article, I will review the role played by ICNA in the past 2 decades to promote education and qualified training in child neurology worldwide.

## The Expanding Field of Child Neurology

Child neurology has experienced significant progress, especially in the field of genetics, molecular neurobiology, and

neuroimaging diagnostic techniques.<sup>2</sup> Many neurodegenerative disorders, some poorly defined metabolic diseases and several syndromes associating mental retardation with neurologic or extraneurologic malformations, have been recently characterized. Furthermore, our ability to evaluate and treat neurological disorders in children has improved considerably because of the aforementioned advances in neuroimaging and neuropharmacology, together with the greater availability of more effective etiology-specific interventions.<sup>2</sup>

Unprecedented developments in pediatric neurosciences are increasingly blurring the traditional boundaries between neurology and psychiatry.<sup>3</sup> Over the past decade, there has been a surge of interest in the neural basis of cognitive development from infancy to childhood, and new pediatric neurosciences that incorporate cognitive neuroscience and neuropsychology are emerging. In Europe, Japan, and the United States, child neurologists are observing a greater demand for medical evaluation of children with intellectual disabilities, learning disorders, autism spectrum disorders, and attention-deficit/hyperactivity disorder at child neurology clinics and increased

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admission of neurobehavioral disorders at child neurology clinics.

A central part of child neurology is currently dominated by the search for genetic factors involved in developmental disorders of the nervous system. However, modern neuroscience has confirmed that brain development is the product of genes and environment interaction. Modern prevention in pediatric neuroscience is based on the concept of targeting known risk factors and enhancing known protective factors that occur early in the chain of the developmental events leading to developmental disorders. Learning, experience, and environmental enrichment were demonstrated to alter brain structure and to produce sustained changes in neural connections.<sup>4</sup> It is now clear that the environment can be manipulated to reinforce stimulation and to maximize brain plasticity. Therefore, early interventions, age-specific psychoeducational programs, and developmentally appropriate approaches (cognitive behavioral therapy and preschool intervention) can have crucial benefits to maximize brain development and reach the best possible outcome.

### **The Increased Need for Training**

Seventy percent of children with disabilities live in resource-poor countries, and most of them have neurological diseases. Protein energy malnutrition, dietary micronutrient deficiencies, environmental toxins, and lack of early sensory stimulation can contribute to the high prevalence of neurodevelopmental disabilities in resource-poor countries.<sup>5</sup> It is known that the prevalence of common neurological conditions is higher in resource-poor countries than in the West, but despite this significant burden, there are few medical personnel and diagnostic facilities available for the management of neurological disorders in these parts of the world. Access to up-to-date imaging, genetic, and biochemical tests is very limited in some geographic areas. This is a big problem because delaying diagnosis and treatment can have deleterious effects on a child's development.

In less developed countries, the major problem is, on the other hand, the shortage of fully trained, qualified professionals and the inaccessibility of technology and diagnostic services. There is the need to identify regional centers and reference labs to improve diagnosis in developing countries. In central Asia, the number of qualified professionals has increased in the past few years; however, they are not distributed evenly between urban and rural areas, as about 95% of them are concentrated in the capital cities. The situation is worse in Africa, where many countries have no child neurologists at all.<sup>6</sup> In those countries that do have pediatric neurologists, most have not been able to obtain proper training, often relying instead on a short internship in Western training centers, where clinical and teaching facilities are available. To be beneficial, these training programs should include a mix of direct supervised clinical care of patients, a taught program with formal lectures on common topics, informal clinical and tutorial-style work, and supervised library work.

ICNA has played a major role in bringing child neurology as a distinct specialty to the forefront worldwide, causing many countries to adopt formal training standards. Although the details of this differ, all countries accept the need, in addition to general pediatric training, for training in classical neurological syndromes of children and in the use of modern clinical tools of neurological investigations and the requirement of familiarity with functional brain maturation and with the developmental disorders of cognition and behavior.<sup>7</sup>

### **The International Education Committee**

Education is one of the primary goals and purposes of the ICNA.<sup>8</sup> In 1992, the ICNA established the International Education Committee with the primary purpose of facilitating the training of child neurologists and exploring opportunities for international cooperation in training and research activities. This committee thus worked to enhance cultural and research links across international boundaries, operating as a bridge between the departments of child neurology around the world that were willing to provide training positions and those who sought such opportunities. The specific role of the committee is to establish guidelines for educational activities within the ICNA, to identify educational gaps and initiate strategies to overcome them, to assist in developing regional policies, to develop country-specific teaching courses, and to provide educational material. The committee's task is also to identify specific problems to be addressed in some areas, such as Africa and central Asia. These are regions where current interventions are often not evidence based and there is the need to develop clinical practice guidelines, including the indications for the appropriate use of drugs and diagnostic technologies.

A traveling faculty of senior child neurologists was planned, aiming to advance education in developing countries by addressing the neurological issues and topics most appropriate to the geographic context. The ICNA Education Committee organized numerous programs aiming to improve the participants' knowledge and attitude on the primary care level of neurological disorders and to promote clinical research interest in the field of child neurology. These clinically oriented events, focused on comprehensive aspects of child neurology, have always enjoyed considerable success, having a very positive impact in the regions in which they took place (Table 1). The faculty members gave lectures on the clinically relevant aspects on child neurology and conducted interactive case discussions and/or tutorials on case reports prepared by participants. Emphasis was given to improve the use of relevant diagnostic measures and management. To overcome language barriers, lecturers able to speak local languages were selected to hold some courses. Educational written materials are provided to the participants, and ideas for clinical research projects are discussed in detail. The improvement of teaching and academic skills of local trainers was also one of the main goals of these events. Further duties involve building capacity in regional health services and improving the management of common neurological conditions.

**Table 1.** International Child Neurology Association (ICNA) Educational Seminars

Date	Venue	Local Organizer	ICNA Speakers	International Education Committee Chairman
May 14-16, 1998	Tartu, Estonia	T. Talvik	K. Swaiman, L. Shield	K. Swaiman
May 21-23, 1999	Montevideo, Uruguay	R. Ruggia	K. Swaiman, P. Curatolo, R. Ouvrier	K. Swaiman
November 17-19, 2000	Delhi, India	V. Kalra	C. Newton, D. Stumpf, M. Velickovic	D. Stumpf
April 28-29, 2001	Nairobi, Kenya	C. Newton	L. Epstein, M. Shevell,	D. Stumpf
February 27-28, 2003	Cairo, Egypt	A. Raouf	V. Kalra, P. Curatolo, D. Stumpf, G. Gascon	V. Kalra
August 24-25, 2005	Guatemala City, Guatemala	J. Gramajo	E. Fernandez, S. Rosenberg, P. Curatolo	V. Kalra
June 20-22, 2007	Almaty, Kazakhstan	M. Lepessova	O. Eeg-Olofsson, P. Curatolo, M. Velickovic	P. Curatolo
June 19-21, 2008	Lima, Peru	P. Campos	P. Curatolo, M. Guerreiro, H. Arroyo, G. Agosta	P. Curatolo
September 11-12, 2009	Kiev, Ukraine	V. Martiniuk	O. Eeg-Olofsson, P. Curatolo, M. Velickovic	P. Curatolo

### Sheila Wallace Award

Sheila Wallace had a leading role in promoting the issue of international education and training for developing countries. She spent time traveling to all continents, lecturing to regional child neurology societies.<sup>9</sup> She was able to promote child neurology in 49 countries, disseminating the basic knowledge of the practical use of antiepileptic drugs worldwide. During the Yoshi Suzuki administration, she organized in Cardiff in 1997 a special meeting in which principles of operation were established. In this meeting, the need to foster education in emerging countries by addressing issues and topics appropriate for the geographic context and by providing lasting value for the recipients was strongly emphasized. Dr Ken Swaiman was appointed to launch this program, and he nominated the first International Education Steering Committee of ICNA consisting of Drs Paul Casaer (Belgium), Paolo Curatolo (Italy), Shaul Harel (Israel), and Robert Ouvrier (Australia), 4 past or future ICNA presidents.

Sheila Wallace worked very hard to determine the neurological needs for children in developing countries, and she prepared a survey published in the ICNA newsletter in 2002 that gave some ideas on the state of neurological services, particularly in central Asia, Latin America, and Africa. This survey drew attention to the plight facing children with neurological diseases and their families, namely, that there are simply too few child neurologists to take care of the increasing number of such children, especially those with chronic conditions that require chronic care. The need to identify regional centers and reference labs to improve diagnosis in developing countries has also been stressed.

In 2003, my administration created a special fund to which members from developed countries can donate to support educational initiatives to be held in underserved countries. To honor the great merit Sheila Wallace had in the promotion of the educational program and her special attitude toward developing countries, the Board approved my proposal to establish a Sheila Wallace International Fellowship Award, which allows a child neurologist from a developing country to attend the ICNA congress and visit selected training programs. The purpose of this award is to nurture young investigators who

practice and have received training in emerging countries. Dina El Metwally (Egypt) and Richard Idro (Uganda) were, respectively, the 2006 and 2010 award winners.

### Other ICNA Strategies

Together with ICNA educational programs, a number of different strategies have been adopted to promote education in emerging countries. One of these involved the annual meeting of the ICNA Executive Board, held in conjunction with local or regional child neurology organizations in different sites; ICNA provided speakers and scientific support to local conferences. ICNA had a significant impact on the development of regional child neurology associations, laying the foundations for the progressive creation of a number of regional child neurology societies in Asia (Kazakhstan, India), Africa (Egypt, South Africa), Europe (Albania), the Middle East (Panarabic Society of Child Neurology), and South America (Peru; Fig. 1).

Since 1982, ICNA has offered to its members the International Review of Child Neurology series, a collection of monographs covering an extensive range of topics, including epilepsy, stroke, autism, tuberous sclerosis, head injury, and others, with the aim to present the best in child neurology. Each book is written by an authoritative child neurologist and is peer reviewed and sent to all ICNA members as part of their annual dues. This publication series, which has differentiated ICNA from all regional societies throughout the years, has allowed our organization to spread education worldwide, benefiting particularly those countries that were traditionally underserved. These books analyze a disease with the purpose of providing the reader with the latest updates on basic neurosciences translated in the clinical context.

Ever since it first started operating, one of ICNA's most important activities has been to organize an international congress in a different region of the world every 4 years. These meetings, which were often held in conjunction with local or regional associations, have always been very special events, gathering delegates from all continents. ICNA congresses have often been the place where advances in child neurology were first recorded and where participants have an opportunity to



**Figure 1.** The welcome address of Paolo Curatolo in Lima, Peru (2008).

take advantage of the myriad educational opportunities focused on the most recent clinical and basic research developments.

In 2002, my administration established research as one of the top prerogatives of our society. Not surprisingly, the ICNA has set as its top research priority the worldwide definition of the causes of neurological handicaps in children in various geographic areas of the world, making it possible to prioritize the techniques of prevention and treatment in relation to the region's specific needs. In countries with high childhood population, potentially avoidable etiological factors, such as infections and malnutrition, remain important causes of neurological diseases in children.<sup>6</sup>

Research needs international cooperation, and we have to fight united against the devastating neurological disorders that still affect millions of children worldwide. Building research capacity in emerging countries is urgently needed. ICNA has a unique role in improving international cooperation and promoting clinical and scientific research, by providing a medium through which physicians can exchange opinions at an international level for the advancement of pediatric neurosciences. ICNA benefits from an international network of highly qualified child neurologists and is therefore well equipped to meet the challenges set by the 21st century. The association can play an important role in launching international multicenter therapeutic trials and worldwide research and is set to be the leader of the global campaign for the prevention of both the causes and consequences of cerebral damage. The association could also suggest problems to be investigated, delineate standards, and discuss ways of managing neurological diseases in children. Research collaboration for rare disorders could be greatly facilitated by the ICNA international network.

### Education in Central Asia

In 1998, while I was serving as secretary general of ICNA, I was contacted by Mr Marat Izzhanov, from the Kazakh Embassy in Rome, to explore the possibility of organizing

training courses in Rome in the field of child neurology with the cooperation of an Italian foundation. We made a specific plan for the next years, with the aim of founding in Almaty the first child neurology unit in Kazakhstan. I established a contact with Dr Marzhan Lepessova, who was the head of child neurology at the Almaty State Medical Institute of Advanced Education, and she spent 1 year in Rome devoting her time particularly on epilepsy and developmental disorders. After returning home, she presented her doctoral thesis, and later she became a professor of child neurology. In the following year (1999-2000), 2 young physicians (Dr Altynshash Jaxybayeva and Dr Latina Tekebayeva) from the same Child Neurology Unit had a 6-month training course in Rome, and after returning home, they successfully passed their thesis and obtained PhD degrees in child neurology. In 2006, Dr Rosa Abedimova from the State Centre for Psychiatric Problems attended the Department of Child Neurology and Child Psychiatry at the Tor Vergata University in Rome and, under my supervision, successfully introduced in Kazakhstan new treatment options for children affected by neurobehavioral disorders. Dr Marzhan Lepessova and her group organized a Kazakh Child Neurology Association and have been able to organize every 4 years an international conference for child neurologists, particularly neurologists from central Asian countries. The latest conference was organized in June 2009 jointly with ICNA (Figure 2). The conference included an educational seminar organized by the ICNA Educational Committee and included not only formal lessons but also the discussion of difficult patients.

### Education in Africa

The role of ICNA in Africa started during the Yoshi Suzuki administration with the organization of the first ICNA Executive Board in Cape Town, South Africa, in 1996. This occasion coincided with the foundation of the Paediatric Neurology Developmental Association of Southern Africa. The Egyptian neuropediatric society was founded in 2000, and the first annual meeting was held in Cairo on April 7-8, 2001. Three ICNA speakers (Olivier Dulac, Paolo Curatolo, and Mohamad Mikati) lectured. A second Executive Board meeting was held during my administration in Alexandria, Egypt, in 2004 (Fig. 3). During this meeting, the idea of organizing an international child neurology congress in Cairo was conceived for the first time. Dr Ahmed Raouf Ibrahim took on the responsibility of this challenging project, and many child neurology meetings, including the Child Neurology Mediterranean Congress, have been organized in Egypt since then by myself, in cooperation with the Egyptian Society of Child Neuropsychiatry and the Egyptian Paediatric Neurology Society, chaired by Ibrahim Shoukri.

The 11th International Child Neurology Congress was held in Cairo in May 2010. This congress has been a unique opportunity for African people to meet each other and to try to create a network. During this meeting, the African Paediatric Neurology Association was founded, with the aim to identify training facilities in Africa, establish guidelines to define the main needs, propose the minimal acceptable standard of care, and use clinical



**Figure 2.** The faculty of Almaty Educational Seminar. From left: Valery Zykov, Stanislav Evtushenko, Paolo Curatolo, Marzham Lepessova, Orvar Eeg-Olofsson, Latina Tekebaeva, and Miko Velickovic.



**Figure 3.** The International Child Neurology Association (ICNA) Executive Board in Egypt (2004). From left to right: Mohammed Bessiso, Milivoj Velickovic, Generoso Gascon, Ingrid Tein, Charles Newton, Daune MacGregor, Sergio Rosemberg, Yoshiyuki Suzuki, Kenneth Mack, Raili Riikonen, Xi Ru Wu, Hugo Arroyo, Thomas Reiser, David Stumpf, Peter Baxter, Paolo Curatolo, Orvar Eeg-Olofsson, Ian Wilkinson, Masaya Segawa, Michael Shevell, and Peter Procopis. In 2009, the ICNA Educational Committee supported the effort of Charles Newton to organize the first educational seminar in Nigeria, where the local child neurology association was founded.

research as a tool to improve children's health. During this meeting, chaired by André Venter, Ahmed Raouf Ibrahim, and Joe Wilmshurst, the child neurology needs in Malawi, Uganda, Ghana, and Nigeria were discussed. A global perspective on the significant burden of neurological diseases in the developing world was widely discussed, to increase awareness of the environmental risk to the neurological development of children globally and to generate specific recommendations for reduction of these risks in less developed countries.

## ICNApedia and Future Directions

While ICNA has a long history of accomplishments in education, it is now necessary to act on the basis of a broader vision, taking into account the changing methods of education. The development of the World Wide Web offers for the first time the potential for a global education. ICNA supports a Web site ([www.icnapedia.org](http://www.icnapedia.org)) that provides access to appropriate papers, clinical guidelines, consensus statements, and management protocols. Furthermore, information concerning training programs worldwide is readily available on this Web site, allowing trainees from all over the world to find the best internship opportunities worldwide. The Web site also displays a calendar of all child neurology meetings and events taking place in every area of the world.

Neuropediatricians continue to face challenges in treating patients more efficiently and keeping up to date on all the research being published every day by journals. ICNApedia provides a snapshot of the most important news affecting child neurology as well as a wealth of resources for clinical practice and patient care. Textbooks with continually updated audio-video data will become available and will be posted on the Web. ICNApedia has the potential to become the first choice of every pediatric neurologist looking for professional information and an online opportunity for those who lack alternatives.

ICNA is deeply committed to providing innovative educational and training programs for all professionals involved in the care of children with neurological disorders. The International Education Committee plans to develop a distance learning course in pediatric neurology for the benefit of those who are unable to travel to attend courses and conferences in person.

This could be supplemented by experience at recognized and participating centers. A distance learning program has the potential to bring high education to those who cannot afford it. Unfortunately, a lot of work must still be done to ensure that every child receives the same level of child neurology care. There are still discrepancies in the quality of care between countries and also within the same country depending on the rural or urban area. ICNA is uniquely qualified and well positioned to remedy this deficit by reducing the gap and increasing the level of child neurology care all around the world.

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