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CEREBRAL PALSY SYMPOSIUM
— NEW HORIZON —



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OUR
SPEAKERS



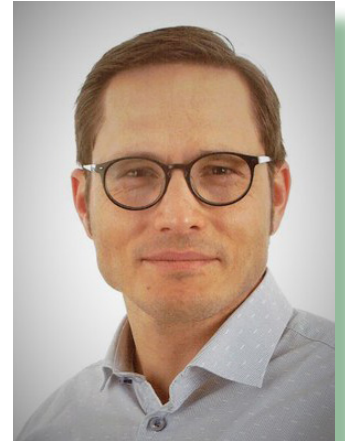
ELEGAST MONBALIU (Belgium)

PROFESSION: Physical Therapist, PhD

PROFESSION TITLE: Professor

BIOGRAPHY:

Elegast Monbaliu leads the Neurorehabilitation Technology Lab (NTL) at Bruges Campus, Belgium. His team's mission is (1) to create the highest independent mobility, (2) to create the highest possible computer access and (3) to optimize objective evaluation of movement disorders in individuals with childhood onset complex movement disorders as cerebral palsy. Within the NTL Bruges, they optimize evaluation and therapeutic rehabilitation interventions for these complex movement disorders & introduce new technologies in this population. In addition, he is secretary of the EACD & president of the 2024 EACD conference Bruges (29/05-01/06/2024) and co-founder of the European Dyskinetic Cerebral Palsy Network.



DATE: October 20, 2023

TIMING: 8:30 am – 9:15 am (EEST time zone)

TITLE: Movement Disorders In Dyskinetic Cerebral Palsy: Definition, Physiopathology, And Management.

ABSTRACT:

Dyskinetic CP is the second largest CP group and dominated by the complex motor disorders dystonia and choreoathetosis. Over the last decade, consensus specific definitions, increasing insights in pathophysiology and measurements have been suggested. However, because spasticity, dystonia and choreoathetosis are often simultaneously present in CP, clinical discrimination is often experienced as difficult and challenging to treat. Yet, good recognition of the condition is vital for targeted medical interventions and rehabilitation to improve daily life activities and quality of life. In the first part, participants will be introduced to the definitions and classification dystonia and choreoathetosis. In the second part, pathophysiology and clinical picture will be overviewed. In the third part, management options and rehabilitation strategies will be discussed.



DIANE SELLERS (UK)

PROFESSION: PhD MA BA MRCSLT

PROFESSION TITLE: Clinical Academic Speech and Language Therapist

BIOGRAPHY:

Dr Diane Sellers has worked as a speech and language therapist for more than thirty years in a variety of settings, with a particular interest in working with children and young people with neuro-disability. She has worked at Chailey Clinical Services for the last 20 years, with specialist responsibility for the assessment, treatment and management of eating and drinking difficulties, sensori-motor speech difficulties and saliva control issues arising in childhood. Diane was the chief investigator for the research project to develop the Eating and Drinking Ability Classification System (EDACS) for people with cerebral palsy (see www.edacs.org). The study received funding for three years from the National Institute for Health Research and Diane completed her PhD based on this study in March 2014. She continues to lead research activity associated with EDACS alongside her clinical work.



DATE: October 20, 2023

TIMING: 9:15 am – 10:00 am (EEST time zone)

TITLE: Eating And Drinking Ability Classification System (Edacs): Purpose, Utility And Potential.

ABSTRACT:

Cerebral palsy (CP) affects children and young people's lives in many different ways, including skills required to eat, drink and swallow. Classification systems have been created to describe how cerebral palsy affects different functional abilities. Each classification system is easy to understand, and provides a common language for use across clinical practice and research.

METHODS:

We consulted with a range of stakeholders to create the Eating and Drinking Ability Classification System (EDACS) from 3 years to adulthood. EDACS describes skills required to eat, drink and swallow in 5 distinct levels of ability, using the key features of safety and efficiency. Subsequent research activity includes: development of Mini-EDACS from 18 to 36 months; retrospective study to examine stability of EDACS over time; and implementing EDACS with adults with CP.

FINDINGS:

EDACS has been adopted globally, with more than 23 translations available from www.edacs.org. We will present findings from our research as well as findings from other research teams using EDACS.



ROSE-MARY BOUSTANY (Lebanon)

PROFESSION: Pediatric Neurology & Genetics

PROFESSION TITLE: Chief, Pediatric Neurology/Neurogenetics/AUB Special Kids

BIOGRAPHY:

Rose-Mary Boustany is tenured Professor of Pediatrics/Adolescent Medicine, Biochemistry/Molecular Genetics at AUBMC & Pediatrics at Duke University. She holds an AUB Board of Trustees Designated Professorship, directs the Neurogenetics Program/AUBMC Special Kids Clinic & is Division Chief of Pediatric Neurology. She founded/headed the Abuhaidar Neuroscience Institute, established a first inpatient psychiatry, child psychology/child psychiatry/psychometric units/Neuro-ICU and a multidisciplinary clinic for dually disabled children in Lebanon. She trained in Pediatrics at AUBMC, Pediatric Neurology at Mass General Hospital, Neurogenetics at the Shriver Center for Mental Retardation & co-directed the Lysosomal Storage Diseases Laboratory all at Harvard Medical School (1980-1988). She spent 18 years at Duke University, becoming Professor of Pediatrics & Neurobiology (1989-2007). She works on the neurobiology/novel therapies for Batten disease, and on prevalence/risk factors/neurobiology/ genetics of autism in Lebanon. She holds American Boards in Neurology/Child Neurology and in Genetics, is member of the Society for Pediatric Research, Fellow of the American Neurological Association, recipient of a Neuroscience/Merck Award, a 2006 Raymond D. Adams Lectureship, a Dubai Harvard Medical Foundation Research grant, and the Sidney Carter Award in Pediatric Neurology. She was reviewer for NIH/Alzheimer Disease Association/FDA and the Boroughs Welcome trust, and was Associate Editor of Annals of Neurology (1996-2018). She is on Boards of the Batten Disease and Research Organization, OpenMinds and the Dibbiyeh Village Community. She holds four patents, 2 of which have issued.



DATE: October 20, 2023

TIMING: 11:00 am – 11:30 am (EEST time zone)

TITLE: 'There Is Always An Underlying Cause'.....

ABSTRACT:

Root causes of 'cerebral palsy', which is now considered outdated will be discussed. Rather, I will elucidate known and unknown causes, treatments and value of correct and timely diagnosis, early intervention, genetic counseling necessity of management required to maintain health and well-being of patients and their families across their lifespan.



ABEER HANI (Lebanon)

PROFESSION: Pediatric Neurologist and Epileptologist

PROFESSION TITLE: Clinical Assistant Professor of Pediatrics and Neurology

BIOGRAPHY:

Abeer J. Hani, MD; Clinical Assistant Professor of Pediatrics and Neurology at LAU with expertise in Pediatric Neurology, Epilepsy and Intraoperative monitoring. She completed her MD training at the American University of Beirut in Lebanon in 2008, then pursued a 3-year residency training in Pediatrics there between 2008 and 2011. She then completed a 3-year residency in Child Neurology at Duke University in Durham, North Carolina in USA between 2011 and 2014, then a 1-year fellowship in clinical neurophysiology, epilepsy and IOM there also between 2014-2015. She is a consultant of pediatric neurology and epilepsy at LAUMC- Rizk Hospital. She is an active researcher with many publications and a member of many local and international scientific committees.



DATE: October 20, 2023

TIMING: 11:30 am – 12:00 pm (EEST time zone)

TITLE: Epilepsy Treatment In Children With Cerebral Palsy

ABSTRACT:

Cerebral palsy is a frequent cause of childhood disability and is associated with multiple comorbidities including epilepsy that impacts 30-50 % of affected patients. It has been well established that children with cerebral palsy and epilepsy often have a more severe seizure burden with frequent hospitalizations due to their seizure recurrence. Use of antiseizure medications continues to be the gold standard of treatment, however other treatment options including surgery, ketogenic diet or vagal nerve stimulation may need to be considered in selected cases.



BASSEM EL- NABBOUT (USA)

PROFESSION: Neurology with Special Qualifications in Child Neurology

PROFESSION TITLE: Neurologist

BIOGRAPHY:

Dr. Bassem El-Nabbout is board certified in Pediatrics, Neurology with special qualification in child neurology , and Headache Medicine. He is also affiliated with the American Academy of Neurology, a member of the American Medical Association, and the Medical Sedgwick Society. Dr.El-Nabbout also serve as a volunteer faculty member at KU-Wichita School of Medicine, Dr. El-Nabbout earned his medical degree from the American University of Beirut. He did his pediatric residency at the American University of Beirut and the University of Massachusetts, then completed a fellowship in pediatric neurology at Duke University Medical Center in North Carolina. He worked for five years at Arkansas Children's Hospital in Little Rock where he was the director of Cerebral Palsy, Neurofibromatosis, and Headache Clinic. He then moved to Wichita in 2009 and worked at Ascension Via Christi Hospital for 10 years before opening his private practice at Kansas Pediatric Neurology Center.



DATE: October 20, 2023

TIMING: 12:00 pm – 12:30 pm (EEST time zone)

TITLE: Botulinum Toxin Injection for Spasticity Management



ISMAT GHANEM (Lebanon)

PROFESSION: Professor of Orthopedic Surgery, Pediatric Orthopedic Surgery, MSc in Biomechanics

PROFESSION TITLE: Director of the Pediatric Orthopedic Program – Faculty of medicine – St Joseph University

BIOGRAPHY:

Ismat Ghanem is Professor of Orthopaedic Surgery, Pediatric Orthopedic Surgery, MSc in Biomechanics (ENSAM, Paris – France). He is currently the Chief of the Orthopedic surgery department Hotel-Dieu de France Hospital Network; Saint Joseph University, Beirut - Lebanon.

His main fields of interest are Neuro-orthopedics, Congenital anomalies, spinal deformities and Bone tumors. He promoted collaboration between engineers and clinicians, by co-founding the Biomedical engineering module – Ecole Supérieure des Ingénieurs de Beyrouth – USJ. He is co-founder and co-director of the gait and biomechanics laboratory, St Joseph University.

Ismat Ghanem is member of various scientific societies, SOFCOT, EPOS, POSNA, IPOTT ..., and is currently board member of the IFPOS (International Federation of Pediatric Orthopedic Societies), and Formerly General Secretary of European Pediatric Orthopedic Society (EPOS), and member of EPOS nomination committee. He is reviewer and board member of many journals (CORR, RCO, OTSR, JPOB, JCOR, BMC, ...) and was organizer or co-organizer of more than 15 local or international conferences. Professor Ghanem was 7 times best paper award winner in international conferences, and was 30 times invited speaker and visiting professor in many countries. He has 125 scientific publications in peer review journals and 35 chapters in books or encyclopedias.



DATE: October 20, 2023

TIMING: 12:30 pm – 1:00 pm (EEST time zone)

TITLE: Orthopedic Intervention In The Upper Limbs In Children With Cerebral Palsy



HANNES HABERL (Bonn, Germany)

PROFESSION: Board Certified Neurosurgeon
PROFESSION TITLE: Professor; Senior Consultant

BIOGRAPHY:

Board Certified Neurosurgeon

Actual Position
Senior Consultant
Center of Expertise for Neurosurgery, Epilepsy Surgery and Spine Surgery
Schön Klinik Vogtareuth

2016 - 2021
First German Chair for Pediatric Neurosurgery
University Hospital
Rheinische Friedrich-Wilhelms-Universität Bonn

2015 - 2016
Head of the Section of Pediatric Neurosurgery
University Clinic Ulm

2011 - 2014
Founder and Head of the First German Independent Department of Pediatric Neurosurgery
Charité
University Hospital Berlin

Publications
author and co-author of more than 200 peer reviewed articles and several book chapters

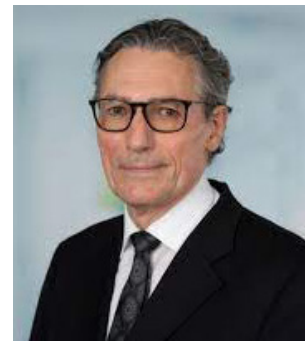
Awards:
Since 2018
Knight of the Order of the Red Cross
Republic of Estonia

DATE: October 20, 2023
TIMING: 1:00 pm – 1:30 pm (EEST time zone)

TITLE: Challenging Traditional Treatment Strategies: The Potential of Selective Dorsal Rhizotomy

ABSTRACT:

The turbulent history of SDR dates back to the early 20th century. Since 1991 a monitoring-guided single-level technique emerged, which allows a safe and early intervention in children with spastic CP. This technique results in an almost complete elimination of spasticity. Today monitoring-guided single-level SDR has been performed successfully in more than 6000 patients. Only recently, the fundamental preventive potential of early elimination of spasticity and the game-changing implications for subsequent therapy concepts are realized.



KATINA PETTERSSON (Sweden)

PROFESSION: CPUP Child-coordinator, Orthopedic coordinator Västmanland, physiotherapist

PROFESSION TITLE: CPUP coordinator Sweden, PhD

BIOGRAPHY:

I have worked as a physiotherapist with children and adults with disabilities for the last 25 years in Västmanland, Sweden and have been part of CPUP (Cerebral Palsy follow-Up Program) as a clinician since 2005, when the program started for Habilitation physiotherapists in Västmanland. Today I work as a Orthopedic coordinator for children with disabilities, at the Habilitation center Västmanland. Since 2015, I have been a member of the CPUP Children's committee Sweden, and I am today CPUP Child-Coordinator for Sweden. I did my PhD defense in 2019, with the title "The spine in cerebral palsy" and I also work as a researcher at Centre for clinical Research Västmanland Hospital, Uppsala University.



DATE: October 20, 2023

TIMING: 2:30 pm – 3:00 pm (EEST time zone)

TITLE: Cpus Program For Hip Surveillance – The Swedish 30 -Year Experience

ABSTRACT:

CPUP (Cerebral Palsy follow-Up Program) has existed in Sweden since the 90s and is today a part of everyday life for children with cerebral palsy (CP), and today also for adults with CP. The presentation will address how CPUP Sweden is structured and how we systematically follow up and work with children and adults with CP. Through this systematic, non-surgical way to follow individuals with CP, we have drastically reduced the number of hip dislocations, reduced pain, scoliosis, windswept hips, contractures, and surgery in children with CP. Through the research done through our registry, but also through other countries' registries, knowledge about CP has increased.



ANTOINE HARIKA (Lebanon)

PROFESSION: Ortho-Prothesiste

PROFESSION TITLE: Product manager

BIOGRAPHY:

Graduated since 1994 from Italy specialized in prosthetics and Orthotics. As product manager at Centre Harika, I have pursued the latest in technology in this field. Other than using the best techniques in the world (such as myo-electrics, bionics, micro processed knees and feet). We have implemented the first and most advanced solution for fabricating the prosthesis and orthosis using the Cad Cam technology. By this we have been the first central fabrication center in the Middle East.



DATE: October 20, 2023

TIMING: 3:00 pm – 3:30 pm (EEST time zone)

TITLE: Splinting In Cerebral Palsy

ABSTRACT:

The fabrication of custom-made orthotics, afo kafo, upper and lower limbs.

Taking measurements from plaster to scan, to digital modification, to carving the positive mold and fabricating the thermoplastic devices.



YANNICK BLEYENHEUFT (Belgium)

PROFESSION: Physiotherapist, PhD

PROFESSION TITLE: Professor

BIOGRAPHY:

Professor **Yannick Bleyenheuft** is holder of the Chair for neurophysiological evidences in Intensive Neurorehabilitation (since 2014). She created the Motor Skill Learning and Intensive Neurorehabilitation lab at the Institute of Neuroscience, UCLouvain, Belgium. She has focused her research interest on the development and implementation of the first motor skill learning intensive intervention targeting both upper and lower extremities in children with CP (unilateral and bilateral). She simultaneously investigates the changes induced by this therapy at behavioural & neurophysiological levels.



DATE: October 20, 2023

TIMING: 3:30 pm – 4:00 pm (EEST time zone)

TITLE: Habit-Ile, An Intensive Intervention Increasing Autonomy And Participation In Children With Cerebral Palsy .

ABSTRACT:

Hand and Arm Bimanual Intensive Therapy Including Lower Extremities has gained a growing interest since its development in 2011.

This motor-skill learning based intervention uses functional goals defined by the children and their parents to promote autonomy and participation. Its effectiveness has been demonstrated in children with both unilateral and with bilateral CP, and the observed functional improvements have shown a link to neuroplastic changes. This keynote will focus on the key principles of HABIT-ILE, the improvements obtained in different subgroups of children with CP at the level of motor and non-motor functions, and the changes induced in autonomy and social participation.



ABIR MASSAAD (Lebanon)

PROFESSION: Pediatric Physiotherapist / PhD

PROFESSION TITLE: Assistant professor

BIOGRAPHY:

Abir Massaad has been a pediatric physical therapist for over two decades. She currently serves as the head of the research and development department at SESOBEL and holds the position of assistant professor at Saint-Joseph University of Beirut and Clinical team supervisor at High Hopes Pediatric Therapy center in the UAE. She holds a Ph.D. in Biomechanics, and has authored numerous publications on the subject of 3D gait and musculoskeletal alterations in children with cerebral palsy.



DATE: October 20, 2023

TIMING: 4:00 pm – 4:15 pm (EEST time zone)

TITLE: Child-Specific Intensive Therapy Program In Children With Cerebral Palsy Presenting With Mild To Severe Impairments Based On SESOBEL Experience.

ABSTRACT:

The aim of this study was to investigate the impact of a child-specific physical therapy intensive program on motor function in children with CP presenting with mild to severe motor impairments.

51 children with CP, were enrolled between 2021& 2023 (mean age: 12 ± 9 y), based on a consecutive sampling method. 20 ambulant (GMFCS levels I, II&III) and 31 non-ambulant children (GMFCS levels IV&V) have benefited from a 4-week child-specific intensive physical therapy intervention of 90-minute, 3 times per week, in addition to a home program. GMFM-88 total and stratified percentages were compared before (T0), after (T1) and at 10 months (T2) of completing the intensive program. The stratified percentage scores targeted standing, walking, running and jumping in ambulant children and lying, rolling, sitting, kneeling and crawling in non-ambulant children. Correlation between changes in Δ GMFM-88 (GMFM-88 score at T1 minus GMFM-88 score at T0) and GMFCS levels were also investigated. Goal Attainment Scale changes based on the T-score calculation was compared between T0 and T1.

The mean value of the total GMFM-88 percentage significantly increased at T1 (mean $\pm$ SD: $46.5 \pm 32\%$ vs $44 \pm 32\%$; $p < 0.0001$) compared to T0. Stratified percentage score has increased at T1, in ambulant ($68 \pm 20\%$ vs $72 \pm 17\%$, $p = 0.001$) as well as non-ambulant children ($33 \pm 20\%$ vs 36 ± 18 , $p = 0.01$) compared to T0. Delta GMFM was negatively correlated to GMFCS levels ($r = 0.67$, $p = 0.004$) (Fig.1). Long term outcomes revealed a significant increase of GMFM-88 total percentage score at T2 compared to T0, however no difference was noted between T1 and T2 (Fig.2).

GAS T-score was significantly increased in T1 compared to T0 (31 ± 10 vs 51 ± 14 , $p < 0.001$).

A 4-week child-specific intensive program improve gross motor function in ambulant and non-ambulant children with CP. This improvement is maintained after almost one year of completing the program. Future studies will explore the efficacy of implementing 2 intensive period per year compared to the standard care.

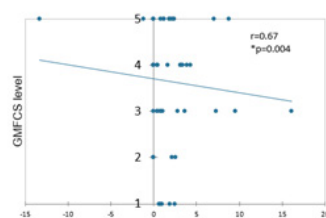


Figure 1: Relationship between GMFM total score changes (Delta GMFM) and GMFCS levels

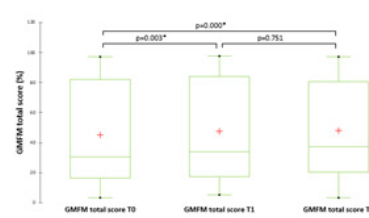


Figure 2: Comparative GMFM total score between T0, T1 and T2

SUZANNE ANDARY (Lebanon)

PROFESSION: Senior SLP

PROFESSION TITLE: Head of the Speech Therapy unit at SESOBEL

BIOGRAPHY:

Over the past decade, **Suzanne** has worked as an SLP specializing in communication, speech, language, feeding, and voice therapy in various contexts, driven by a strong commitment to supporting children and young adults with diverse and severe disabilities. She has worked at SESOBEL for eight years, where she presently leads the team of SLPs, overseeing the assessment and treatment of various challenges, especially those related to eating & drinking, as well as the implementation of advanced AAC technology.



DATE: October 20, 2023

TIMING: 4:15 pm – 4:30 pm (EEST time zone)

TITLE: Chewing Training In Children With Cerebral Palsy (Cp): Combining Motor And Functional Exercises.

ABSTRACT:

Introduction

Chewing alterations are often described in children with cerebral palsy (CP) [1,2].

While oral motor exercises (OME) are usually recommended to improve swallowing function and physiology [3], the current level of evidence on the effect of OME on chewing is poor [1]. Passive and active exercises are used to treat chewing alterations, however, oral-motor intervention programs, including functional exercises where food is introduced, have never been described.

Aim to evaluate the effect of a treatment protocol combining passive, active and functional exercises on chewing.

Methods

17 children with CP (age: 4.8 ± 1 year old, GMFCS II and III: $n=3$, GMFCS IV and V: $n=14$, EDACS I and II: $n=9$, EDACS III, IV: $n=4$, EDACS V: $n=1$), presenting chewing alterations were enrolled. The Mastication Observation and Evaluation (MOE) [4] was used to evaluate oral motor behaviors of chewing before (T0) and 9 months (T1) after completing a 4-step treatment protocol. Passive and active motor exercises were conducted in the same session, followed by functional exercises that incorporated the introduction of food. The MOE total score, along with the score of each item forming the total score, was compared between T0 and T1 using the Wilcoxon signed-ranks test.

Results

MOE total score increased in T1 (20 ± 3 vs 18.6 ± 3 , $p=0.003$) compared to T0. While all the scores attributed to each specific function tended to increase in T1 compared to T0, only two functions showed a significant increase in T1 compared to T0: Tongue protrusion (2.2 ± 0.7 vs 2.6 ± 0.7 , $p=0.05$) and lateral tongue movement (2.3 ± 0.5 vs 2.6 ± 0.6 , $p=0.023$).

Conclusion

Combined active, passive and functional exercises could be helpful to improve chewing in children with cerebral palsy.

References:

[1,2] Averdson 2010,2013; [3] Gisel et al. 2000; [4] Remijn et al. 2014.



PETER ROSENBAUM (Canada)

PROFESSION: Developmental Paediatrician

PROFESSION TITLE: Professor

BIOGRAPHY:

From the beginning of my formal specialty training in London in 1970 and my academic appointment at McMaster University in 1973, I have had a career-long focus on childhood disability. In addition to busy clinical services over my first 25 years in the field, I have worked with colleagues in many countries in health services research to explore our field's issues, with the goal to understand what we do to help children and families, why we do those things (what are the ideas behind the actions?), and how our thinking has evolved over the past 50 years. This has led to work with graduate students at several universities around the world, invited lectures in >30 countries, research, writing (>450 peer-reviewed papers and book chapters and co-authorship of five books), and the promotion of new ways to think, talk, and act in order to support children's development and family wellbeing in the face of neurodisabilities.



DATE: October 20, 2023

TIMING: 5:00 pm – 5:45 pm (EEST time zone)

TITLE: Understanding Cerebral Palsy Through The Lens Of Who's Icf And CanChild's F-Words: How Does This New Perspective Help Kids, Families And Service Providers?

ABSTRACT:

The WHO's 2001 framework for health – called the International Classification of Functioning, Disability and health (or 'ICF') – has transformed our thinking about what we can do in the field of childhood disability, including cerebral palsy. This integrated set of ideas brings together the biomedical, psychological/personal, and social/environmental threads of people's lives into a single comprehensive 'picture' that allows us to 'rule in' relevant aspects of each individual's story and create a unique narrative as the basis of our work as service providers. CanChild's 'F-words for Child Development' bring the ICF ideas to life and have captured the attention and imagination of families and colleagues around the world. This talk will take listeners on a journey from our past traditions to current thinking, and suggest how these ideas can and should shape all our work with children with cerebral palsy and their families. The talk will also provide evidence of the impact and uptake of these ideas, and challenge everyone to reflect on new opportunities to be helpful!



ROSLYN BOYD (Australia)

PROFESSION: Physiotherapist, PhD

PROFESSION TITLE: Professor of Cerebral Palsy Research

BIOGRAPHY:

Professor of Cerebral Palsy & Rehabilitation Research, Faculty of Medicine, The University of Queensland, Brisbane, Australia. Scientific Director, Queensland Cerebral Palsy and Rehabilitation Research Centre, Children's Health Research Centre, Faculty of Medicine, The University of Queensland.



Professor Roslyn Boyd	Professor of Cerebral Palsy and Rehabilitation Research, Faculty of Medicine, The University of Queensland.		
INSTITUTION AND LOCATION	DEGREE	YEAR	FIELD OF STUDY
La Trobe University, Melbourne	PhD	2004	Human Biosciences
University of East London	M Sc	2001	Physiotherapy
Uni of Strathclyde, Glasgow	Pgrad dip	1997	Biomechanics
Uni of New South Wales, Sydney	B Sc (Anatomy)	1980	Science Anatomy
Uni of Sydney, Cumberland College	B App Sc (Physio)	1981	Science Physiotherapy

Honors and Awards

Commendation for the Premier's Award for Medical Research (Victoria), June 2004.

Gayle Arnold Award for best paper at the American Academy of Cerebral Palsy & Developmental Medicine, in both 2011, 2010 and 2014 (first Australians to receive the award).

Mentorship Award, 2017 The Faculty of Medicine, The University of Queensland.

Mentorship Award 2018, American Academy of Cerebral Palsy and Developmental Medicine.

Professional Biography: Professor Boyd has primary training in Physiotherapy (Pediatrics, Neurological, Neonatal, Orthopaedics) with post graduate training in Biomechanics (Pgrad) and Neuroscience (PhD). She has an international track record in conducting randomised clinical trials in the field of cerebral palsy (on the efficacy of early interventions, upper limb rehabilitation, and evidence-based Neurorehabilitation). Dr Boyd's studies have combined clinical outcomes with an understanding of the mechanisms underpinning response to intervention with novel use of Advanced Brain Imaging (functional MRI, Diffusion Imaging, Functional Connectivity, CP connectome). Her strong collaborations in neuroscience have enabled the development of novel rehabilitation trials including early Upper limb rehabilitation (REACH), early multi-modal rehabilitation in Low resource contexts (LEAP), Participation focused interventions, parenting interventions for infants, children and youth with Cerebral Palsy. Dr Boyd has achieved 12 national NHMRC project grants, 2 NHMRC partnership implementation grants and is CIA/CIB on two NHMRC Clinical Centres of Excellence. She is passionate about training the next generation of researchers and in 2014 received the research supervision excellence award in the Faculty of Medicine and Science at UQ for post graduate training (including 27 PhD completions, in the fields of Rehabilitation, Neuroscience, Neonatology, Nutrition and Physical Activity. Dr Boyd is the IAACD Co-chair on the 4th IAACD joint conferences (Heidelberg, 2025).

Refereed Journal Articles: Total Publications >345 peer reviewed publications over her career. H index=49, at 15 years after completion of her PhD with an average. 19.46 citations per article; (Researcher ID: A-4498-2011).

DATE: October 21, 2023

TIMING: 8:30 am – 9:15 am (EEST time zone)

TITLE: Early Detection And Neuro-Restorative Rehabilitation For Children With Cerebral Palsy

ABSTRACT:

Early detection and neuro-restorative rehabilitation for children with Cerebral Palsy

Roslyn N Boyd, PhD (Neuroscience), MSc (Physiotherapy) 1,2,

Professor of Cerebral Palsy Research.

1 Queensland Cerebral Palsy and Rehabilitation Research Centre, Faculty of Medicine, The University of Queensland.

In the next 30 minutes another child with Cerebral Palsy (CP) will be born, however on average their parents will not have a confirmed diagnosis until the child is 19 months old and most of their window of neuroplasticity will be closed. Two international Clinical Practice Guidelines have recommended very early detection in the first 5 months of life and that children commence early neurorehabilitation for children at high risk of Cerebral Palsy (CP). They provided a strong recommendation for use of General Movement's Assessment at fidgety age (Se 98%, Sp 90%) and structural MRI at term to detect CP in infants (to classify infants as "high risk of a later diagnosis of CP") followed by the Hammersmith Infant Neurological Exam (HINE, Se 90%). In our systematic review Structural MRI performed at term corrected age (in preterm infants) was a strong predictor of CP, with sensitivity ranging in individual studies from 86 to 100% and specificity ranging from 89 to 97% (Bosanquet et al. 2013). Newer advanced brain imaging techniques such as diffusion imaging offer new opportunities to quantify networks for brain integrity using connectomes (Panneck et al. 2014, Saha 2020).

So what intervention should we be referring to after early detection at 12 weeks post term. Interventions need to promote early development of the visual system (VISIBLE, Guzzetta), early upper limb development (Boyd REACH) with child active goal directed early neurorehabilitation and an enriched environment provide potential for early neuroplasticity (GAME Morgan). Interventions to promote brain reorganisation in response to Baby CIMT are safe and feasible (Eliasson, Baby CIMT) and infant friendly Bimanual training leads to equal improvements in hand skills (Greaves Baby BIM, REACH Boyd 2017). Two international clinical practice guidelines have been published to highlight the state of the science for early detection and early intervention for children with CP (Novak et al. 2017, Morgan et al. 2020). Our current plan is to develop a toolbox of clinical, HD EEG, MRI, genomic and microbiome biomarkers to identify infants at high chance of CP and other adverse neurodevelopmental outcomes (Autism, FASD) in the few months of life in order to fast-track families to evidence based early interventions. Our research on the efficacy for activity-based therapies has implications for the dose, context and density of optimal upper limb intervention for children with UCP (UCP) (Sakzewski et al. 2013). The essential elements of effective activity and Participation focused interventions include: (1) intensive activity based task-practice with repetition; (2) progressive incremental increase in difficulty and; (3) goal directed approaches to enhance motivation and engagement in therapy (4) engagement of families using a home based coaching model that is (5) in context. Lessons have been learnt from our research of neurorestorative rehabilitation in school age children and their families (Jackman 2022) that have impacted our current clinical trials of early intervention for infants identified early with CP.

References:

1. Bosanquet M, Copeland L, Ware R, Boyd RN. A systematic review of tests to predict cerebral palsy in young children. *Developmental Medicine & Child Neurology*. 2013;55(5):418-426.
2. Novak, I., Morgan, C., Adde, L., Blackman, J., Boyd, R. N., et al. (2017a). Early, Accurate Diagnosis and Early Intervention in CP Advances in Diagnosis and Treatment. *JAMA Pediatrics*, 171(9), 897-907.

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GORDON DUTTON (UK)

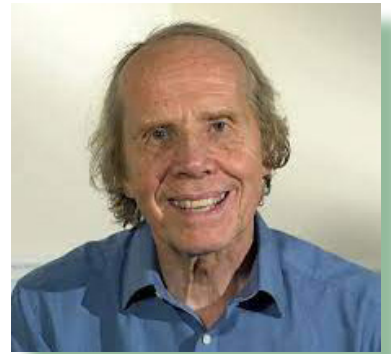
PROFESSION: Paediatric Ophthalmologist

PROFESSION TITLE: Professor of Visual Science

BIOGRAPHY:

Professor **Gordon Dutton** is a Paediatric Ophthalmologist who worked for over 20 years at the Royal Hospital for Sick Children in Glasgow. He is now Emeritus Professor of Visual Science at Glasgow Caledonian University. His current special interests include medical education and cerebral visual impairment (CVI) in both children and adults.

Professor Dutton has lectured as a Keynote Speaker on a range of ophthalmic topics in relation to pediatric ophthalmology, both nationally and internationally. He has contributed to over 200 refereed publications, and to four textbooks concerning cerebral visual impairment in children, as well as to two information websites for teachers and parents, namely 'The CVI Society' and 'CVI Scotland'.



DATE: October 21, 2023

TIMING: 9:15 am – 10:00 am (EEST time zone)

TITLE: Dorsal Stream Dysfunction In Children With Cerebral Palsy

ABSTRACT:

Around 60-70% of children have visual impairments on account of the brain condition that has also caused their cerebral palsy. It is likely that the commonest type of visual impairment is dorsal stream dysfunction. In this condition, visual mapping of the surroundings is deficient, particularly in crowded or noisy environments. This can lead to impairments in visual search, which becomes worse and can give rise to distress in crowded environments. Moreover, this condition is also accompanied by inaccuracy of limb and body movements (called optic ataxia) which compound the motor difficulties caused by the cerebral palsy.

This talk sets out to explain this complex neurological disorder & to outline how we can identify and help affected children.



ANITA EL HAJJ (Lebanon)

PROFESSION: Pedagogue – Orthopedagogue – Executive PhD

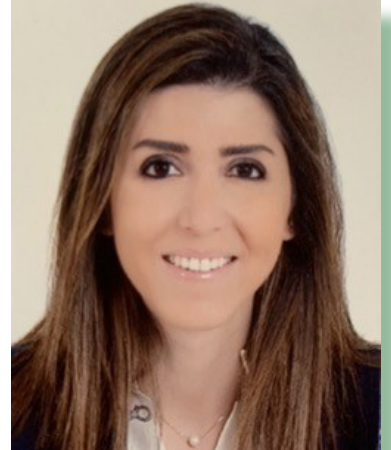
PROFESSION TITLE: Director of the educational department at SESOBEL

BIOGRAPHY:

Dr. Anita Youssef El hajj is an Education Expert holding an Executive Doctorate in Business Administration from Paris-Dauphine University and Saint Joseph University, Beirut. Since 2004, she has been actively involved in the field of Special Education. Currently, she is the Head of the Educational Department at SESOBEL and works as Education Expert at the Ministry of Education and Higher Education in Lebanon.

Dr. Youssef El Hajj is also a lecturer at both Saint Joseph University and Holy Family University. And she is a researcher in the field of Management, with two published articles and numerous presentations at international conferences.

Over the past 20 years, Dr. Youssef El Hajj has pursued valuable specialized training in Education & Special Education from institutions in the United States, France, Belgium, and Lebanon.



DATE: October 21, 2023

TIMING: 10:15 am – 10:30 am (EEST time zone)

TITLE: Empowering Lives Through A Specialized Educational Moving Forward On The Path To Personal Growth & Fulfillment

ABSTRACT:

Within a complex and turbulent Lebanese context, individuals with Cerebral Palsy face significant challenges such as limited access to education, barriers to employment opportunities, and a lack of specialized facilities and services, etc. This issue raises the question: how can specialized education and holistic support improve these individuals' life?

This presentation defines the action of SESOBEL which has been contributing to the Personal Growth and Fulfillment of individuals with cerebral palsy since 1976. It highlights the impact of SESOBEL's mission on the lives of thousands of children, youth, and adults and their families: SESOBEL helps individuals lead a happy and hopeful life despite all difficulties.



Danielle Gerlach (France)

PROFESSION: Specialized Pedagogue

PROFESSION TITLE: Trainer

BIOGRAPHY:

Danielle Gerlach, Specialized Pedagogue.

European Expert Trainer. Specialized education consultant.

Experiences: in hospitals, in institutions, in families, regardless of age or disability, in France and abroad.

Certified by Andreas Fröhlich to disseminate "Basal Stimulation Approach".

Co-Founder of "Groupe Stimulation Basale France®".



DATE: October 21, 2023

TIMING: 10:30 am – 11:00 am (EEST time zone)

TITLE: "Basal Stimulation" In Cerebral Palsy Presenting With Severe To Profound Difficulties Based On Body, Cognitive And Sensory Support

ABSTRACT:

The Basal Stimulation approach by Professor Frohlich is a holistic and transdisciplinary approach that encourages the exploration of sensory, motor, communicational, relational and emotional competences of persons with disabilities.

Basal Stimulation is not a technique or a treatment method but a qualified way to adapt to the individual's life situation by providing him with appropriate opportunities for perception, communication and movement.

At SESOBEL – Lebanon, Basal Stimulation has been integrated into the program of children with severe to profound cerebral palsy since 2003. Currently, more than 160 beneficiaries benefit from it.

After 20 years of integrating this approach, based on the quality of accompaniment and on living together, we have been able to ensure the overall well-being and development of our beneficiaries at all levels. This has been achieved through a deep understanding of their individual needs and adapted practices to support them optimally and help them live a happy life.



Ghada Kmeid (Lebanon)

PROFESSION: Pedagogical Coordinator - Trainer

PROFESSION TITLE: Pedagogical Coordinator - Certified Trainer In Basal Stimulation

BIOGRAPHY:

Pedagogical coordinator at SESOBEL, Lebanon.

Certified trainer in "Basale Stimulation nach Prof. Dr. Fröhlich®"

Affiliated to the Basal Stimulation French Group (GSBF) and the International Association for Basal Stimulation (AISB) based in Germany.

20 years of experience in Specialized Education with the integration of "Basal Stimulation" with children, youth and adults with motor and/or intellectual disabilities or with Autism Spectrum Disorder.



DATE: October 21, 2023

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HILDA KHOURY (Lebanon)

PROFESSION: Educator, PhD

PROFESSION TITLE: Director of the Directorate of Guidance and Pedagogical Counseling in Schools at the Ministry of Education and Higher Education

BIOGRAPHY:

Hilda El Khoury is the Director of the Directorate of Guidance and Pedagogical Counseling in Schools (DOPS) at the Ministry of Education and Higher Education (MEHE). DOPS takes part in educational strategy and policy-making and oversees the promotion of quality education in public schools.

Ms. El Khoury was previously the Head of the Official Exams directorate at MEHE for three years. She achieved the digitalization of the official exams system and the accommodation of the official exams to the needs of learners with disabilities.

At DOPS, Hilda established the Child Protection Unit and led the development, launch, and roll-out of the Child Protection Policy. She manages the inclusive education project in public schools and the development of the National Policy for Inclusive Education. Furthermore, she has improved health education and led the "School Health Guide" development. During the COVID-19 pandemic, she represented MEHE in the committee established by the Cabinet and led the development of "The COVID-19 Preventive Measures Guidelines" in addition to coordinating the shift to remote and hybrid learning and the safe return to school and supervising the launching of the call center to receive all complaints for disasters and schools well-being topics and follow up on all cases. Hilda supervised the establishment of a coaching system and the development of observation tools to ensure qualitative follow-up.

Ms. El Khoury is a trained Maths teacher and holds M1 in Mathematics, M1 in informatics, and a Master's in Education. She is a holder of a Ph.D. in the Science of Education and has held a range of previous positions: teacher trainer; mathematics coordinator, and education consultant in a variety of schools.



DATE: October 21, 2023

TIMING: 11:00 am – 11:15 am (EEST time zone)

TITLE: Challenges Related To The Inclusive Education In Lebanon

ABSTRACT:

This presentation explores the theme of inclusion within the Ministry of Education and Higher Education and its associated policies. It sheds light on the collaborative efforts between the Ministry and SESOBEL, with a particular focus on the region of Jezzine. The discussion revolves around the journey from establishing integrated schools to achieving a more inclusive educational landscape in Lebanon. The presentation aims to illustrate the importance of inclusive education in promoting diversity, equity, and unity within Lebanese society, ultimately contributing to a more inclusive Lebanon.



SIBELE SERHAL (Lebanon)

PROFESSION: Psychomotor therapist

PROFESSION TITLE: Head of the Inclusive Education Program at SESOBEL

BIOGRAPHY:

Sibele Serhal is licensed in "Psychomotor Therapy" from Saint Joseph University in 2012, with a Master's degree in Psychomotor Therapy obtained in 2015. She also holds a Master's degree in "Educational Sciences with an emphasis in School Management." In 2019, she became a therapist specializing in Exchange and Development Therapy for Autism from Saint Joseph University.

In terms of work experience:

- She has been working as a Psychomotor Therapist at Sesobel-Jezzine since 2012, specifically in the program of school integration in public schools.

- She has been a Psychomotor Therapist at Sesobel - Ain el Rihani since 2015.

- Since 2016, she has also been working as a Psychomotor Therapist at DAR-SESOBEL, conducting initial and follow-up psychomotor assessments (SAF).

- From 2012 to 2015, Sibelle Serhal worked as a Psychomotor Therapist at the Lebanese Welfare Association for the Handicapped in Sarafand.

- Since 2019, she has been the head of the Inclusive Education Program at SESOBEL Jezine.

- She started working as an instructor in sports and education at Antonine University in 2021. She also serves as a supervisor for pre-professional internships at the Institute of Psychomotor therapy at Lebanese University since 2021.

Additionally, Sibelle Serhal works as a specialist consultant for private schools in Jezzine, providing training to teachers and conducting assessments for children with difficulties.



DATE: October 21, 2023

TIMING: 11:15 am – 11:30 am (EEST time zone)

TITLE: School Inclusion In Cerebral Palsy: Sesobel Experience Based On A Pilot Project

ABSTRACT:

Since 1990, SESOBEL has been dedicated to promoting the inclusion of children in schools with the goal of preserving the right to education for all. And back in 2006, SESOBEL took the lead in implementing the inclusive education strategy in the public primary school of Jezzine, in collaboration with the Ministry of Education in Lebanon and local communities.

SESOBEL Jezzine was chosen and appointed by the Ministry of Education, as a pioneering project of inclusive education in Lebanon. It provides various services that target children and youth with disabilities as well as students with learning difficulties. The primary objective is to ensure educational inclusion while upholding children's rights to learn and raise awareness in the community about the importance of education and social inclusion.



MARIE BARHOUCHE-ABOU SAAB (Lebanon)

PROFESSION: Physical Therapist; DPT

PROFESSION TITLE: Head of technical aid unit at SESOBEL

BIOGRAPHY:

Marie (Mimi) is specialized in the field of posture, seating and mobility for the past 30 years. She is the head of the Technical Aids Unit at SESOBEL. She is a doctor of Physiotherapy since 2016 and as of last September, she graduated in Posture, seating and wheelchair mobility from the University of Limerick in Ireland. She is a lecturer at Saint Joseph University in Beirut. Marie is passionate about this field. She is a WHO certified trainer for the wheelchair provision Basic and intermediate level. She offered clinical consultations and audit to wheelchair users, clinicians and wheelchair professionals in Lebanon and in the Arab countries.

Marie has developed multiple training courses and workshops on seating and 24Hour Postural management mainly for CP population and neuro muscular diseases. She presented in many conferences in Lebanon, in the European Seating Symposium in Dublin and in the International Seating Symposium in the USA.

Marie is known as a skilled and experienced clinician and presenter with hands-on and multi-disciplinary view on clinical practice and seating.



DATE: October 21, 2023

TIMING: 11:45 am – 12:00 pm (EEST time zone)

TITLE: Challenges in Assistive Technology (GAATO report)

ABSTRACT:

The Global alliance of Assistive Technology Organizations (GAATO) worked on a global project, in eight regions throughout the world, to identify grand challenges in the area of assistive technology outcomes.

The aim was to identify and clarify the set of current challenges that needed to be addressed to successfully measure assistive technology outcomes and impact at the individual, community, local, national and global level.

SESOBEL was chosen to lead this project in the Middle East region. A total of 35 participants hailing from various Arab countries, including Jordan, Syria, the United Arab Emirates, and Lebanon, actively participated in this consultation. They shared their expertise in Assistive Technology and collectively recognized a series of challenges. These challenges, identified in the Middle East region, have been consolidated with those from other regions for publication. This will serve as a guide for future conversations and research in the area of Assistive Technology Outcomes.

This presentation will present the set of challenges reported in the Middle East region and will focus on the specific challenges impacting the work of specialist and experts in assistive technology in Lebanon.



BART VAN DER HEYDEN (Belgium)

PROFESSION: Physical Therapist, Wheelchair Seating Specialist

PROFESSION TITLE: PT

BIOGRAPHY:

Bart has specialized in the field of seating, wound care and mobility for the past 28 years. After studying physical therapy in Gent, Belgium, he gained experience in Germany providing seating and therapy for children with Cerebral Palsy. After working in a rehab setting in the USA he offered clinical consultations to wheelchair users, clinicians and manufacturers worldwide. He has also started a physical therapy practice with his wife in Belgium.

Bart has developed multiple training courses and workshops on skin management, seating assessment, seating techniques & interventions for different user populations. He has presented for seating specialists all over the world and he developed a seating approach for clinical problem solving and maximizing outcomes.

Bart is known as a skilled and experienced clinician and presenter with a global, hands-on and multi-disciplinary view on clinical practice and seating.



DATE: October 21, 2023

TIMING: 12:00 pm – 12:30 pm (EEST time zone)

TITLE: 24-Hour Postural Management – Can The Findings From The Physical Seating Assessment Technique Guide Us?

ABSTRACT:

A 24-hour postural management program is a planned approach for all postural orientations available to the individual such as lying, sitting and standing. The aim is to preserve and / or restore body shape. Benefits include increased functional ability, maintain muscle length, maintain skeletal alignment, reduce the progression of deformity, reduce fatigue, manage pressure and enhance breathing, swallowing, digestion.

Focus is often placed on seating an individual in a seating and standing system but positioning in lying is often neglected. There is a strong link between lying and sitting posture. This presentation will explore the link between lying and sitting and will cover physical assessment techniques for a 24-hour postural approach.



CAMILLE MATTÀ (Lebanon/UAE)

PROFESSION: Applied Mathematics and Computer Engineer

PROFESSION TITLE: Assistive Technology Professional

BIOGRAPHY:

An Applied Mathematics and Computer Science graduate from University of Houston, Texas; **Camille Matta** spent over 38 years in the field of Information Technology.

What started as a field experiment with touchscreens for the Autism Center in Kuwait, grew to a passion in specialized technology for the Disability sector. He worked closely with Assistive Technology in the Middle East for people with various disabilities.

Over the last 17 years, Camille began the work of preaching Assistive Technology in the Middle East among Centers, Therapists and Parents of Special Needs children by providing energetic, innovative, and practical guidance in the development, implementation, and delivery of special needs software, hardware, and educational tools.

Camille attended and participated in many International trainings and seminars which enhanced his knowledge and experience in Assistive Technology. Camille attended and completed several ICT and specialized AT training courses adding to his knowledge in this field. He is an active speaker and presenter and trainer in the field of Assistive Technology in addition to his ability to assist in providing AT Assessment for people with special needs.



DATE: October 21, 2023

TIMING: 12:30 pm – 1:00 pm (EEST time zone)

TITLE: Clinical Practice And Guidelines In Assistive Technology

ABSTRACT:

This presentation aims to provide speech therapists, occupational therapists, parents, and pediatricians with an overview of the clinical practices and guidelines surrounding the use of assistive technology for children and adolescents living with cerebral palsy.

Cerebral palsy is a complex neurological condition that can significantly impact a child's motor and communication abilities. Assistive technology plays a pivotal role in enhancing their quality of life by providing tools and solutions to overcome challenges.

This presentation will also highlight the impact of Assistive Technology on the Assessment process subjected to people with cerebral palsy at all stages of their development.



GINNY PALEG (USA)

PROFESSION: pediatric physiotherapist from Silver Spring, Maryland, USA

BIOGRAPHY:

Ginny Paled is a pediatric physiotherapist from Silver Spring, Maryland, USA. For the past 19 years, she has worked with children aged 0-3 years in homes and childcare, with a focus on the F-words. Ginny earned her master's degree in physical therapy at Emory University and her DScPT at the University of Maryland Baltimore. Ginny specializes in posture and mobility assessment and interventions for children at GMFCS Levels IV and V. She is certified in Precht General Movement Assessment (GMA) and the Hammersmith Infant Neurological Exam (HINE) and trained in Routines Based Interventions (McMaster) and coaching (Sheldon and Rush). She has published over 20 peer-reviewed journal articles on standers, supported stepping devices, and power mobility. She is the lead author for the American Academy of Cerebral Palsy Hypotonia Care Pathway and past Chair of the AACPDM Communications Committee and a member of the Nominating Committee. She served on the Scientific Committees for the AACPDM and EACD in 2022.



DATE: October 21, 2023

TIMING: 2:00 pm – 2:45 pm (EEST time zone)

TITLE: Early Mobility In Cerebral Palsy

ABSTRACT:

It is now possible to identify children at high risk for non-ambulatory CP. The GMA-MOS score (2-5 mos) below 8 and HINE score (4-24 mos) below 40 indicate the highest need for ON-Time mobility. This means providing supported standing, stepping and independent mobility at the age appropriate time (9-15 months adjusted age). This course will review the research and highlight some practical clinical applications.



MELANIE WARDAN (Lebanon)

PROFESSION: Psychologist

PROFESSION TITLE: Head of Psychology Unit at SESOBEL

BIOGRAPHY:

Melanie Wardan is a passionate clinical psychologist and psychotherapist with over 5 years of experience in the field of disability. Her commitment to the mental health of individuals with disability has made her a trusted expert in the field.

Melanie Wardan earned her M.A. in Clinical Psychology from the University of Balamand (UOB). She went further to earn a Psychodynamic Psychotherapy diploma, which is currently her specialty. She is currently a recognized member of the Lebanese Order of Psychologists (LOPsy).

Possessing a deep understanding of human behavior and passion for aiding individuals, Melanie has successfully treated a wide range of psychological conditions among individuals with disability, including anxiety disorders, depression, and post-traumatic stress disorder. Her eclectic approach in therapy aids individuals link their past experiences with their current thought and behavioral process.



DATE: October 21, 2023

TIMING: 2:45 pm – 3:15 pm (EEST time zone)

TITLE: From Childhood To Adulthood: The Social And Psychological Challenges Of Individuals With Cp And Their Families

ABSTRACT:

Cerebral Palsy, a child-onset disorder, is a well-researched topic. However, the availability of research on the psychological challenges and experiences of individuals with CP and their family is scarce. Through its experience, SESOBEL has gathered qualitative material related to the psychological experiences of individuals with CP from their childhood years until adulthood. In addition, SESOBEL put emphasis on the experiences of the families, i.e. parents and siblings. This presentation will tackle the previously-mentioned challenges, as well as, the role and impact of SESOBEL in aiding individuals throughout their journey.



ELIAS TAWK (Lebanon)

Youth with disability at SESOBEL.

PROFESSION TITLE: Volunteers & Visitors Unit Assistant At Sesobel - CEO Assistant

BIOGRAPHY:

Elias Tawk, a determined and inspiring youth with cerebral palsy, currently holds important roles at SESOBEL, a dedicated organization for the welfare of children with disability in Lebanon. He excels as a key member of the Visitors and Volunteers Unit, as well as the CEO's assistant. In a testament to his entrepreneurial spirit, Elias has also established a successful bakery "Sajjery" showcasing his resilience and dedication to achieving his dreams and to inspiring others "through his journey"



DATE: October 21, 2023

TIMING: 3:15 pm – 3:45 pm (EEST time zone)

TITLE: Experience Of A Young Person With Cerebral Palsy

ABSTRACT:

A movie of an inspiring journey through the life of Elias Tawk, an exceptional individual with unwavering determination. Despite facing significant challenges due to disability, Elias has triumphed and made a mark as a valuable member of Sesobel. We invite the public to witness his incredible story in an upcoming short film, showcasing his resilience, achievements, and how he has overcome adversity to carve a path of success and empowerment.



GISELE KARAM (Lebanon)

PROFESSION: Social worker

PROFESSION TITLE: Director of social department at SESOBEL

BIOGRAPHY:

Gisèle Karam, is a social worker with more than 32 years of experience in the social sector, serves as the Head of the Social Department at SESOBEL, LEBANON. Her expertise extends across various domains, including mediation, ethics, the protection of minors, community development, and social work, as evidenced by her multiple certifications. Over the years, she has effectively disseminated this wealth of knowledge through over 90 training sessions conducted for NGOs, universities, and hospitals.



DATE: October 21, 2023

TIMING: 3:45 pm – 4:15 pm (EEST time zone)

TITLE: Participation As A Constructive Dynamic In The Life Projects Of People Living With Cp: Overview And Perspectives

ABSTRACT:

This project aims to enhance the involvement of individuals with Cerebral Palsy (CP) in their life project, shifting from passive to active participation. It offers a guide to empower individuals with CP, along with essential support from professionals, families, and other important agents in order to highlight the means of supporting individuals with special needs throughout their journey. The objectives include, but are not limited to, fostering autonomy, promoting inclusive environments, and building supportive communities.



MIRNA MZAWAK (Lebanon)

PROFESSION: Social Science, PhD

PROFESSION TITLE: Associate Dean for Research at the Faculty of Arts and Sciences and the Director of the IDEES Research Laboratory

BIOGRAPHY:

Prof. Mirna Abboud Mzawak, is a distinguished scholar with a Ph.D. in Social Sciences. As the Associate Dean for Research at the Faculty of Arts and Sciences and the Director of the IDEES Research Laboratory, she has played a pivotal role in fostering research excellence.

Beyond academia, she is a tireless advocate for a multitude of social causes, including but not limited to women's right through leading the synodal process on women, and most importantly the rights of people with special needs being a member of the General Assembly of Anta Akhi. Her commitment extends far beyond a singular cause, reflecting a deep dedication to fostering inclusivity and social development.



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JOAQUIM ALVARELHÃO (Portugal)

PROFESSION: High Education Professor

PROFESSION TITLE: Professor

BIOGRAPHY:

José Joaquim Marques Alvarelhão is a Full Professor at the Health Sciences School, University of Aveiro (Portugal), where he teaches and supervises bachelor, master, and PhD students in Health Sciences.

Research interests include human functioning, emphasizing environmental factors related to disability. He has been involved in several European and nationally funded research projects and has more than 30 research publications distributed by books, book chapters, journals, and communications at international conferences.



DATE: October 21, 2023

TIMING: 4:15 pm – 4:30 pm (EEST time zone)

TITLE: Participation Of The Parents: Parents Engagement In Research «Family Faculty»

ABSTRACT:

The communication will address strategies for involving families and people with disabilities in research activities described in the literature, exploring the current trend of shifting from a passive role to a participatory and influential role. Simultaneously, it will try to describe the potential implications of this engagement not only in knowledge transfer but also in social and health support functioning.



JOHN COUGHLAN (Luxembourg)

Father of a 16-year-old with spastic quadriplegia (GMFCS IV)

PROFESSION TITLE: Secretary General of the International Cerebral Palsy Society (ICPS), member of the Steering Committee of the new Civil Society Commission of the World Health Organization

BIOGRAPHY:

John Coughlan is Secretary General of the International Cerebral Palsy Society (ICPS), a non-profit organisation with members in over 50 countries on all five continents, mainly associations for people with cerebral palsy (CP), their families and the professionals who work with them.

Based in Luxembourg, of Irish and British nationality, John is the father of a 16-year-old with spastic quadriplegia (GMFCS IV).

His work for ICPS focuses on advocacy, capacity-building and knowledge-transfer for CP-focused organisations, as well as the dialogue between persons with lived experience and the research community. He was recently appointed a member of the Steering Committee of the new Civil Society Commission of the World Health Organization.



DATE: October 21, 2023

TIMING: 4:30 pm – 5:00 pm (EEST time zone)

TITLE: Participation Of The Children And The Parents In The Project Of Life (Testimony)

ABSTRACT:

John Coughlan is the father of a 16-year-old boy with cerebral palsy (spastic quadriplegia, GMFCS IV). In an interactive presentation drawing on his own experience, he will explore the ways in which childhood-onset disability is not just a medical condition that needs to be managed, but an all-consuming life project that challenges the child, their family and society as a whole. He will argue that the participation of the child and their family in a global approach will both empower them and help professionals to understand better their needs and capacities, ensuring better outcomes for all.

