



Dear Partners,

It almost feels surreal reviewing our year given the current situation our country is facing. However, we are once again reminded of how acutely essential our work in the community is. As so many fellow citizens face poverty and other extremely challenging realities, we must always bear in mind the additional hurdles individuals with special needs face in terms of access to proper healthcare, education, and employment. Sadly, many associations and NGOs that cater to special needs have closed their doors or discontinued their valuable services, resulting in an even bigger need for OpenMinds to continue on its path.

Thanks to your generous donations and our tireless work, OpenMinds managed to cover significant ground in 2019 in assisting families, schools, and the progress of local research. We also continued on our mission of opening minds and developing awareness within our community. This newsletter depicts our numerous accomplishments this year.

While the future remains somewhat unclear, we at OpenMinds remain resolute in fulfilling our mission and in contributing essential services the community has come to expect from us. Going forward, the road may be tougher but, as they say, when the going gets tough, the tough get going!

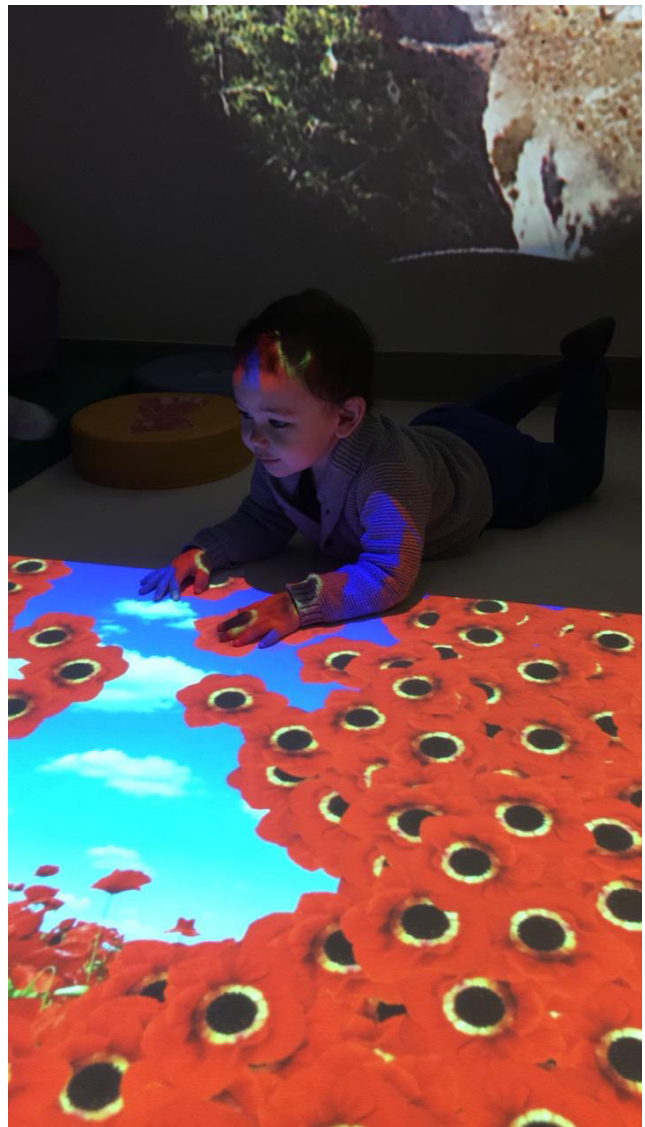
We look forward to a more prosperous Lebanon in 2020 and in every year to come.

Mrs. Ghida Rabbat
President, OpenMinds

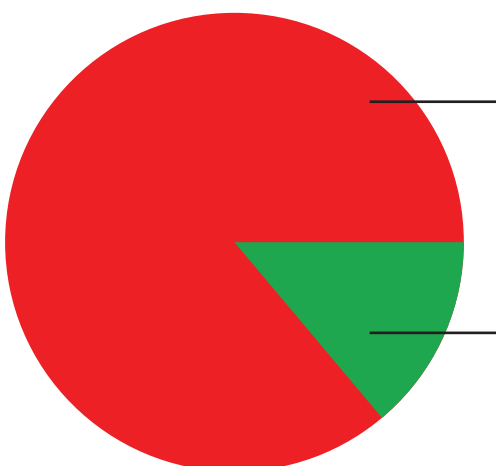
Rose Mary Boustany, MD
*Professor of Pediatrics/Adolescent Medicine &
Biochemistry/Molecular Genetics
Director, Neurogenetics Program/AUBMC
Special Kids Clinic, AUB
Adjunct Professor, Pediatrics, DUMC/Duke*

MEDICAL PACKAGES

We are in the throes of transformation and conflicts yet to be resolved. These will affect all our lives in Lebanon and the region, particularly services to families in need. The prevalence of special needs is 1/10 children in ordinary times. During times of conflict and unrest, this figure becomes 1 in 5 children! The new number of families with one or more children with special needs assisted by OpenMinds packages in 2019 is 75. To date, this number is now 415, with many waiting in the wings.



In 2019



75% of patients assisted were males

25% of patients assisted were females

ASSISTANCE TO SCHOOLS AND TRAININGS

OpenMinds is proud to have helped three additional schools by reinforcing and enhancing their support services for students with special needs. This brings our total number of schools helped since 2012 to 25.



Khaled bin Al Waleed Al Horj Makassed school:

The refurbishment of the sensory room offered by OpenMinds.

Shouf National College:

The refurbishment of the School Learning Support Department.

Heritage College:

The award of eight active panels ensuring better learning opportunities for all students.



OpenMinds continued its partnership for the third year with Trait D'Union, a resources and orientation center. Trait D'Union assists mainstream public/private schools by providing training and support for the implementation of inclusive practices, enabling the schools to handle special needs students. Thus far, 15 schools have been trained.

The results are encouraging and show that **Trait D'Union's** intervention alongside the teachers is fruitful and helping children make important progress. In a snapshot, below are some of the results:



200

Teachers
trained



77

Training
Sessions



174

Follow-up
Visits



346

Students
Targeted



22

Awareness
Sessions



939

Participants
in the Awareness
Sessions

1185
Objectives
set in classes



756 objectives
were acquired

408 objectives
were in progress

21 were
not acquired

In line with our mission to further knowledge in education on special needs, OpenMinds carried out a training for 30 teachers, administrative staff and coordinators at Khaled bin Al Waleed Al Horj Makassed raising awareness on learning disabilities and ADHD through the 'Universal Design for Learning' course with Ms. Lara El Khatib.



Noting the scarcity of certified ABA therapists in Lebanon and their availability to work with students locally, OpenMinds embarked on a program created towards increasing the number of such essential professionals locally. As a result, OpenMinds facilitated and financed the training of 6 students in achieving the mission of taking the Board-Certified Behaviors Analyst Exam Certification. By December 2020, 4 of them will be BCBA certified.

TESTIMONIALS

I must say that the BCBA scholarship I received has been immensely beneficial to my personal and professional development. The ABA courses have added value to the quality of therapy I provide to my patients and kept me in contact with the current best practices in the field. It feels like a missing piece of the puzzle has been added; making my educational background, and, practice complete, and, holistic.

I feel privileged to have had the opportunity to pursue these courses that will soon be leading up to my BCBA certification. I would like to extend my gratitude to OpenMinds' board members, for giving me such an opportunity.

Nadine Adhami

I followed the Board Certified Behavior Analysis 18 months coursework and learned a lot about understanding behavior, measuring changes in behavior and assisting caregivers in their mission. The coursework had an enormous added value on my practice as a therapist. It helped me improve the teaching techniques I use with the kids I follow, manage in a better way conduct disorders and behavior problems and finally be more efficient and precise with the support I give to parents and educators in their daily interactions with children and adolescents on the autism spectrum disorder.

I wouldn't have heard about the BCBA coursework and wouldn't be able to attend it without the support of OpenMinds who I want to thank for the opportunity they gave me and for the role they had in making me a better therapist. By funding and supporting this program OpenMinds granted efficient interventions to more children and caregivers and allowed me to take part in the actions they are taking towards our society.

Karen Abou Assi

SCHOLARSHIPS AWARDED

OpenMinds works with families, the community, and professionals in the field of special education. Our mission is to spread awareness and to support proper education and inclusion in the community. In 2018, based on an acute demand from students and schools alike, OpenMinds established a special needs scholarship fund for families in financial difficulty. For the 2019 - 2020 academic year OpenMinds awarded 54 students scholarships in 9 schools and in one nursery school. In order to optimize and ensure success, the schools were chosen from those that OpenMinds had assisted and collaborated with in the past.



The total number of scholarships awarded to date is 88.

RESEARCH AT AUBMC

Times of great uncertainty do not preclude making advances in the health Sciences, either by or discovery of novel genes or development of effective treatments for neurogenetic disorders affecting our children.

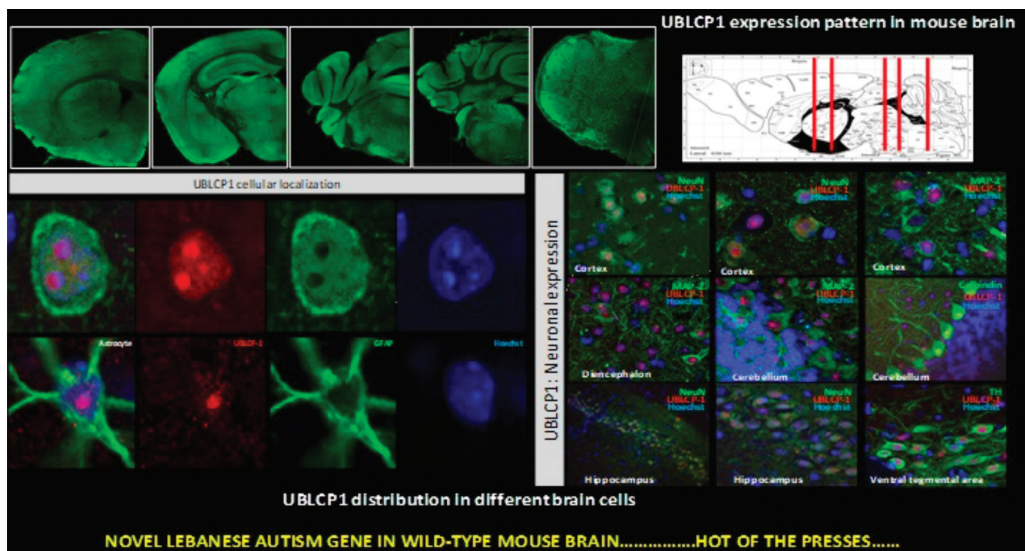
The Neurogenetics Team continues, with very generous and visionary support by **OpenMinds**, to deliver progress in investigation of causes and treatments for developmental and neurogenetic disorders in children. The research projects resulted in **10 publications in international journals and in 8 presentations locally and internationally.**

2019 PUBLICATIONS in International Journals

1. Sally El-Sitt, PhD, Jihane Soueid, PhD, Katia Maalouf, PhD, Nadine Makhoul, Jamal Al Ali, MD, Joelle Makoukji, PhD, Bilal Asser, MS, Daniel Daou, BS, Hayat Harati, PhD, Rose-Mary Boustany, MD. Exogenous Galactosylceramide as Potential Treatment for CLN3 Disease. Ann of Neurol; Nov 2019

2. Stephanie Saaybi, Natally Al-Arab, Salem Hannoun, Marithereese Saade, Rayyan Tutunji, Carine Zeeni, Rolla Shbarou, Roula Hourani and Rose-Mary Boustany. Pre- and Post-therapy Assessment of Clinical Outcomes and White Matter Integrity in Autism Spectrum Disorder: Pilot Study. Frontiers in Neurology Aug 19, 2019

3. Al-Rayess, Heba; Lakissian, Zavi; Boustany, Rose-Mary; Sharara-Chami, Rana. A "Snap" of Portable Media Use among Children 2 Years and Younger in a Developing Country. Health and Primary Care. OAT. 2019
4. Hoyek, Rose-Mary Boustany, Christiane El-Haddad. "Eye Tracking Abnormalities in Strabismic School-Aged Children and Effect on School Performance". (2019) British EYE 2019 (in review). Manuscript ID EYE-18-969.
5. Christiane Al-Haddad; Stephanie Hoyeck; Karine Ismail; Maamoun Abdul-Fattah; Larissa Smeets; Mona Krayem; Marie-Therese Saade; Chadi Alam; Rolla Shbarou and Rose-Mary Boustany. Christiane Al-Haddad; Stephanie Hoyeck; Karine Ismail; Maamoun Abdul-Fattah; Larissa Smeets; Mona Krayem; Marie-Therese Saade; Chadi Alam; Rolla Shbarou and Rose-Mary Boustany. Paradigm for Eye Tracking and Vision Screening in Autism. Autism Research (2019). (in review).
6. Sally El-Sitt, Jihane Soueid, Jamal Al Ali, Joelle Makoukji, Nadine J. Makhoul, Hayat Harati, Rose-Mary Boustany. Developmental comparison of ceramide in wild-type and *Cln3 Δ ex7/8* mouse brain & sera. Frontiers in Neurology (2019). 10:128
7. Sally El-Sitt, Joelle Makoukji, Nadine J. Makhoul, Jihane Soueid, Humam Kadara, Rose-Mary Boustany. Galactosyl-ceramide impact on male & female *Cln3 Δ ex7/8* mouse brain gene expression. Sci. Reports (2019). In review.
8. Shbarou Rolla M, Boustany Rose-Mary, Daher Rose T, Pakdel Parisa El Eid Rozana, Nouredine Abir, Karam Pascale E. Experience with non-ketotic hyperglycinemia in a developing country: 14-year retrospective study. Neuropediatrics, 2019
9. Elias Salameh, Mona Krayem, Maritherese Saade, Reem Yassin, Serene Anouti, Rose-Mary Boustany. Impact of screen time on severity of symptoms in autism spectrum disorders. (2019) submitted to JADD.
10. Zainab Awada, Reem Akika, Rihab Nasr, Arafat Tfayli, Rose-Mary Boustany, Joelle Makoukji, Hani Tamim, Akram Ghantous, Nathalie K. Zgheib. Short Relative Telomere Length in Peripheral Blood and Tissues Is Associated with Breast Cancer. (2019) Clinical and Translational Oncology (in review).



2019 PRESENTATIONS IN LEBANON/ EUROPE/USA

St Georges Hospital, Balamand Medical School:

Idraac: mental disorders Conference (Jan 28, 2019)

-Genetics of autism and other stories.

Closed Roundtable on BIOBANKING IN LEBANON:

Bio-banking in Research and Medicine

Duke University Medical Center. March 2-5, 2019

- Duke Pediatric Neurology & Developmental Medicine Update 'From patient to gene & molecular therapies' (March 2, 2019)

- Duke Division of Pediatric Neurology Presentation: Autism in Lebanon- (March 3, 2019)

- Duke Department of Pediatrics Grand Rounds: Galactosylceramide to treat CLN3 disease (March 5, 2019)

American University of Beirut.

-AUBMC 16th Pediatrics Review Course:

Neurogenetics and Genomics in Pediatrics (June 29, 2019)

-Pompe Disease Conference AUBMC/Sanofi at AUBMC: Sep 21, 2019

-Plenary speaker: "Trauma, Stress, and Neurodegeneration" IBRO school, Beirut, Lebanon. NOVEL FINDINGS IN AUTISM IN LEBANON.(October 4, 2019). Characterization of the UBLCP1 gene; Flupirtine Derivatives in the CLN3 mouse(Oct 7, 2019)

Ministry of Foreign Trade and Development

(Kingdom of the Netherlands). Amsterdam: Level Segment of Conference on Mental Health and Psychosocial Development, . AUTISM AND SPECIAL NEEDS IN LEBANON.

In Memoriam. GR DeLong, MD, The) Oct 19, 2019.

1st Global Pediatric Neurologist: A Eulogy. Exeter, New Hampshire.

Society for Neuroscience (Chicago, IL)_ Oct 20-23.

Posters presented on the UBLCP1 gene and Flupirtine Derivatives in CLN3.



Our lives are dedicated to yours

cme.aub.edu.lb

LYSOSOMAL STORAGE DISEASES ACROSS THE LIFESPAN

MODULE 1: POMPE DISEASE

September 21, 2019

Helim and Aida Daniel ACC Building, Multipurpose Room, AUBMC Beirut, Lebanon



opentargets
NABI K. BASH
LIFE SCIENCES INSTITUTE
AMERICAN UNIVERSITY OF BEIRUT

ana3adi CAMPAIGN

Today, the likelihood of a child being diagnosed with any form of a neurodevelopmental condition is 1 in 65. These special individuals end up having to cope with a systematic lack of provision of rights, resources, and services. They face exclusion at all levels of their daily lives and find themselves struggling to defend their basic rights. Their right to normalcy becomes more and more evasive.

The **#ana3adi** campaign was officially launched by **OpenMinds** during its 6th annual gala in April 2019, with the screening of five short movie clips addressing the yearning of “special” individuals to be treated as regular peers. The campaign highlights the necessity for genuine acceptance and inclusion of Special Needs Individuals in schools and in the workplace.

In a world where everyone is trying to be different, many yearn to be “regular”.





“HIRE ME” BY RANDY LEWIS

OpenMinds, under the patronage of the Ministry of Labor and the Ministry of Social Affairs and in collaboration with Quest Education, held a workshop on October 17, 2019 called “**Hire Me**”. OpenMinds invited the world renowned **Randy Lewis** to present ideas and to discuss various ways in which businesses could include special needs individuals in their workforce.

During his 16 year tenure as Walgreens’ chief supply chain officer, **Mr. Lewis** pioneered a disability hiring model that resulted in 20% of Walgreens logistics workforce being composed of people with disabilities who perform the same jobs, earn the same pay, and are held to the same performance standards as fellow team members. His efforts have been hailed as the most successful initiative of its kind, with many companies such as Microsoft, Loewe’s, and Marks and Spencers copying his model.

The workshop proved to be incredibly successful as reflected in follow up surveys conducted later. In the presence of the Minister of Labor, Mr. Richard Kouyoumjian, and a representative for the Minister of Labor, Mr. Camille Abou Sleiman, 62 attendees from 32 different companies attended the extremely informative and interactive workshop. Most of the attendees invited were business owners or HR managers from the banking, tech, insurance, pharmaceutical, retail, distribution, governmental, manufacturing, advertising, hospitality and educational sectors.

Later that afternoon, **OpenMinds sponsored** a lecture in collaboration with the AUB **Suliman S. Olayan School of Business**, where Mr. Lewis gave a talk on “**Why I Hired A Workforce No One Else Would**” to 60 Graduates of the Business school.

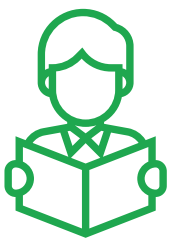
The remaining events planned for the following day had to be abruptly cancelled due to the unfolding events in Lebanon.





EMPLOYMENT COLLABORATION

The **I Can Work** program developed by **Step Together Association** and funded by **OpenMinds** is designed to integrate students with learning difficulties in the workplace within the community, under the supervision of a coach and a coordinator. In its third year running, the program has managed to have:



30 Students
between 16 and 22



in Workplaces
comprised of
small to medium
enterprises such as

- supermarkets
- barbershops
- restaurants
- pharmacy
- library
- nursery



Pinnacle Partners

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