Issue 6, Newsletter 6, Spring/Summer 2018







**66** SINCE OUR LAST ISSUE, WE ARE PLEASED TO ANNOUNCE THAT OPENMINDS HAS ASSISTED HUNDREDS OF FAMILIES AT THE AUBMC SPECIAL KIDS CLINIC **9** 

# **OPENMINDS GALA DINNER**

OpenMinds and the AUBMC Special Kids Clinic held their 5th annual fundraising dinner on Thursday February 22, 2018 at the Seaside Arena in Beirut, in the presence of Prime Minister Saad Hariri and a host of prominent political, business leaders as well as social figures.

The magical evening began with Tania Kassis performing the Lebanese national anthem "a capella", followed by a musical interlude by Nancy Ajram and an exceptional fashion show by Elie Saab. During the gala, the beautiful children of the Tania Kassis Academy Choir performed a number of songs and dances that enthralled the audience. The evening program was presented by Wissam Hanna. The lineup of the gala included the screening of two documentary films about OpenMinds, a tombola and a public auction of paintings donated by the internationally renowned artists Nabil Nahhas, Ayman Baalbaki and Marwan Sahmarani.

During the evening, OpenMinds revealed further details of the assisted living village for individuals with special needs in Dibbiyeh. Once executed, the project will be the first of its kind in Lebanon and the Middle East. The village would provide vocational education, organic farming, exhibition and retail spaces, and a small hotel. The carefully designed community aims to serve as a "safe haven for people with special needs, contribute to their integration, happiness, leisure and financial independence and provide them with sustainable care throughout their lifespan."



OpenMinds is proud to have helped four additional schools by reinforcing and enhancing school support and services for students with special needs.

# SAGESSE BRASILIA AND SAGESSE PLUS



OpenMinds was a primary partner in the major refurbishing of the premises for students with special needs at the Sagesse – Brasilia school. The initial goal of the project was to renovate a floor within the school dedicated to inclusive education. The project was expanded in light of the enthusiasm and vision of Father Superior of the College, Reverend Father Pierre Abi Saleh, and Father Tony Karam. Thanks to their ambitious ideas, the pilot project will now provide necessary support for special needs students in a natural setting, and expand such services to a wider student population after school hours. The center was inaugurated in September of 2017 and has a capacity of 60 students.

# **BEIRUT BAPTIST SCHOOL**

OpenMinds support to Beirut Baptist School (BBS) in the heart of Beirut, has led to significant expansion, enhancement, and accommodation for its Special Education program. The program identifies students with learning difficulties and provides them with appropriate academic, social, and emotional interventions within the school curriculum. The vision of BBS is to reduce gaps between student current performance and developmental levels. Special educators, therapists, and teachers cooperate collaboratively to help students reach their ultimate potential. A new department under construction with support from OpenMinds will house this program that will enable enrollment of additional special needs students.

#### **AHLIAH SCHOOL**



OpenMinds granted Ahliah School in Beirut in April 2018 funds to support its inclusion program. The collaboration enhances Ahliah programs, particularly for students with learning difficulties, by providing resources and training. The grant will be used to purchase specialized educational resources for the school. Part of the professional development support provided by OpenMinds, included a workshop conducted by Ms. Lara Khatib on the practice of differentiated instruction in mainstream classroom environment.

Ahliah School Classroom

# SHOUF NATIONAL COLLEGE

OpenMinds granted funds in May 2018 to Shouf National College to refurbish the Learning Support Department and its resources at the school. This work is in progress and will be completed in time for the 2018-2019 academic year.



Elie Saab Fashion Show





### TRAIT D'UNION SERVICES



Trait d'Union Teacher's Workshop

OpenMinds partnership with Trait D'Union, a resources and orientation center, established by the Foyer de la Providence and the Institut Européen de Coopération et de Développement, continues for the second year. Trait d'Union assists mainstream public/private schools by providing training and support for the implementation of inclusive practices involving parents, teachers, and therapists. OpenMinds renewed funding of training sessions to seven private schools and donated additional funds for training and materials for partner schools.

# WORKSHOP

A two-day workshop, geared towards educators and caregivers, took place at the Issam Fares conference hall at AUB, on May 25 and 26, 2018.

### **"MAXIMIZING STUDENT PROGRESS"**

OpenMinds was extremely fortunate to be able to host Dr. Ronald Leaf, Director of Autism Partnership and Behavior Therapy and Learning Center at CABA (Center for Advancement of Behavioral Analysis) in Seal Beach, CA, USA for a two-day workshop at the Issam Fares conference hall at AUB, on May 25 and 26, 2018. Dr. Leaf, a leading world authority in behavioral management, provided participants with practical and helpful information and experience in the implementation of intensive behavioral treatment methodologies. Training included an overview of developmental disabilities and applied research, principles of behavior analysis and management, a description and explanation of treatment programs and curricula, and demonstration of these teaching methods. Over 200 individuals signed up, ranging from teachers and classroom aids, to therapists working with children with developmental disabilities, psychologists, and parents. Attendees found the workshop to be insightful, inspirational, and incredibly helpful.



onald Leaf, PhD & OpenMinds Board Members



Ronald Leaf, PhD

# CONFERENCES

Our very own Dr. Rose-Mary Boustany, thanks to OpenMinds support, had the opportunity to share some of her research findings in two highly visible conferences: "Autism in Lebanon: 2018" presented on April 19th, 2018 as part of the 49th Middle East Medical Assembly at the Academic and Clinical Center (ACC) conference hall at AUBMC, and, another on "Positive Impact of GalCer on CLN3 disease" presented on May 5th, 2018 as part of the Recent Advances in Rare Diseases conference (RARD2018) in New Delhi.



Meeting (RARD2018) in New Delh

Both were attended by adult and pediatric neurologists, psychiatrists and psychologists, therapists and geneticists from all over the world.

# **COLLABORATIVE WORK WITH OTHER NGOS**

OpenMinds takes pride in helping and collaborating with other NGOs to provide the greatest benefit to the community.

### LEBANESE AUTISM SOCIETY (LAS)



In the fall of 2017, OpenMinds and LAS collaborated to relocate and refurbish the LAS Center for Autism Intervention and Research (CAIR). The center provides support to individuals with autism in adaptive living skills, independent living arrangements, supported employment, education, social skills development and recreational opportunities. It was inaugurated in March 2018 in the presence of HE Minister Pierre Bou Assi and members of OpenMinds.

# STEP TOGETHER ASSOCIATION

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 coordinator. The program, established in October 2017, is geared towards students 16 to 18 years of age. Goals are to equip students with job-readiness skills and ways to be successful at work through real work experiences, didactic teaching and analysis of experiences. In April 2018, provided work opportunities included a restaurant, two hairdressing salons, a supermarket and a home appliance shop. The workplace within Step Together also includes a bakery workshop. Over the last six months, students in this highly successful endeavor have improved social skills and this has heightened their self-esteem. Future plans include searching for new work opportunities that welcome more students with special needs.



# NEXT STEP AUB

n continuation of its support of Next Step AUB, OpenMinds provided smart classroom equipment to the program, ncluding an interactive panel and tablets for all students. Next Step AUB is a highe career education program for young adults with intellectual disabilities like Down Syndrome.



Dr. Rose-Mary Boustany



Next Step AUB students - Smart

# OUT AND ABOUT IN THE COMMUNITY AND BEYOND

We enjoy supporting and taking part in activities occurring within and outside the community!

• We would like to thank Mr. Ali Wehbi for choosing to dedicate his official Guinness Book World Record to autism during his AUTISM TOGETHER run from March 31 to April 2, 2018.



• Thank you College Notre Dame de Jamhour Class of 2018 for promoting and supporting OpenMinds during the highly successful end of year event, "SHINE ON".

• Inclusion starts at nurseries! OpenMinds was proud to be part of the Syndicate of the Professional Nurseries in Lebanon's Conference "For a Sustainable Education in Early Childhood' in collaboration with the Lebanese German University in April 2018. Innocent Minds Nursery and OpenMinds hosted a presentation on the importance of integration and early intervention. • During the awareness week in April themed "Accepting Differences", the Tres Saint Sacrament School in Jbeil invited OpenMinds for a talk on autism aimed at primary school students. OpenMinds shared presentations, videos and questions on the topic.





The syndicate of the Professional Nurseries in Lebanon

• High Hopes, a sponsor and strong supporter of OpenMinds in its mission and activities established a specialized early intervention therapy center in Dubai in December, 2017. The center has benefitted from the experience and support of the ASKC, and, they are off to an amazing and stellar start.

# **CLINICAL PACKAGES AND UPDATES**

In four and a half years 316 families and their children have received medical assistance with sound diagnosis, genetic counselling, family guidance and support, therapies and other services. The ASKC cohesive unit made up of parents, therapists, physicians, clinic assistants and nurses have accompanied special needs children on their journey of progress and joy, overcoming challenges, together. Their celebrations, trials and tribulations are now permanently etched as a valuable measure of the ASKC-OpenMinds-Community experience.

# FOLLOW-UP NEWS-EPISODE 3:

• **Episode 1:** A 2.5 year old refugee child assisted by OpenMinds since 2015 was diagnosed with Hurler disease and received free medical care at ASKC and AUBMC. She successfully received enzyme replacement therapy, generously donated by the compassionate care program, courtesy of Sanofi-Genzyme.

• **Episode 2:** In 2017 she underwent a successful bone marrow transplant from her younger brother. A third pregnancy was monitored early with prenatal diagnosis generously donated by CentoGene. The parents now have a second bouncing baby boy free of disease.

• **Episode 3:** : In 2018, the child and her family were repatriated to the United Kingdom where she is thriving and receiving continued medical care...happy end of story.



Shahd and her brother



# RESEARCH

OpenMinds continues to support numerous research projects carried out at the ASKC and the Neurogenetics laboratory at AUBMC. These include studying effects of a number of drugs for the NCLs, a group of fatal childhood neurogenetic disorders, AND, projects detailing previously unknown findings of neuroradiological improvement, visual tracking differences, novel genes and impact of early intervention on outcome in autism. The fruits of this labor in 2018 include:

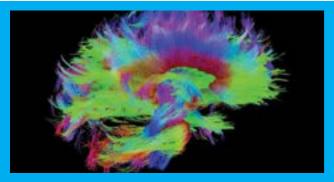
• Completion of a PhD project and thesis by Sally El-Sitt on February 5, 2018 entitled: Exogenous Galactosylceramide as potential treatment for CLN3 disease.



Sally El-Sitt at work

• Six poster presentations presented in March, 2018 on AUB Biomedical Research Day, with Stephanie Hoyek et al., garnering best poster award at Biomedical Research Day 2018 for their work on Visual Tracking Abnormalities in Autism.

• Another two posters will be presented at the 16th NCL International Conference at Royal Holloway College, London in September, 2018. Nine publications have been submitted with four already published.





For more detailed information on the research projects and publications, please visit: www.openmindslebanon.org/research/research-projects-publications

# AN EXCEPTIONAL SALUTATION

To our 'Pinnacle & Prized Partners' for their unwavering support.

#### THANK YOU

# **Pinnacle Partners** G

**MR. & MRS. BOB MANOUKIAN** 



# **Prized Partners**















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