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## NEWSLETTER 3, FALL 2015

Dear Partners, Sponsors, Friends and Family,

Our country and our region are on a rollercoaster ride yet, we at OpenMinds and the AUBMC Special Kids Clinic, cannot but count our blessings and be thankful for the generous support we continue to receive from you.

Much has been accomplished since our last newsletter, whether in the realms of recreation, education, employment, helping families and special kids in need, or in research into autism and neurogenetic diseases. None of this would have been possible without you, the wind beneath our wings.

We have big dreams at OpenMinds including providing the best medical care, creating inclusive environments at all levels of education, extracurricular activities, employment and housing, all the while increasing happiness and companionship for our kids that are fast reaching adulthood. We will make it all happen, especially with you cheering us on.

We wish you, the country and the region a joyous and peaceful upcoming holiday season.

On behalf of us all and the many families you have helped, we say a very big **THANK YOU!**



\* The OM Family celebrating their many blessings and you!

GHIDA RABBAT  
 President, OpenMinds

ROSE-MARY BOUSTANY, MD  
 Director, AUBMC Special Kids Clinic

Partners



### OpenMinds Patient/Family Packages: \$608,081 committed and more

Since March 2014, OpenMinds has been able to assist over 85 families in need, because of your generous patronage. The services we covered were diagnostic evaluations, hospitalizations, surgeries, expensive yet essential state of the art genetic testing, provision of multidisciplinary care, and one on one therapies for premature babies, children on the autism spectrum, and those with learning disabilities and congenital anomalies. **Very importantly, exact molecular genetic diagnostic tests, accomplished during early pregnancy, have helped prevent the recurrence of progressively debilitating and deadly genetic illnesses, allowing families to anticipate, worry free, the arrival of their bundles of joy!**



### OpenMinds Funds Research: Thinking Globally but Acting Regionally

OpenMinds is the first NGO to have the foresight and vision to support basic and clinical research into neurogenetic and neurodevelopmental conditions at a local, but internationally relevant and significant, level.

**AUTISM:** Your generous philanthropic spirit has allowed OpenMinds to support the work of Dr. Boustany at the ASKC clinic and the neurogenetics program at AUBMC for the past two years. The unwavering and steadfast backing has resulted in furthering knowledge into the epidemiology and prevalence, genetic and environmental causes for autism in Lebanon.

Together, the outstanding clinical services provided by the clinic and the funding of research by OpenMinds have propelled the ASKC clinic and neurogenetics program at AUBMC to become a **CENTER FOR EXCELLENCE IN AUTISM SERVICES AND RESEARCH**. This funding has spurred interest in autism and has led to productive collaborations across AUB to include the Faculty of Health Sciences, Pediatric Neurology, Ophthalmology, General Pediatrics, and Neuroradiology.

**RESEARCH INTO PEDIATRIC GENETIC NEURODEGENERATIVE DISEASE:** The Boustany laboratory also focuses on the study of a group of neurogenetic disorders called the NCLs. After identification of genes and basic pathobiology *the goal now is to come up with therapies for these otherwise fatal diseases*. Thanks to support from OpenMinds, the work has glimmers of hope of coming up with medications that can halt the progress of these devastating diseases.

**AUTISM RELATED RESEARCH:**

1. *The hunt for Autism Susceptibility Genes in The Lebanese Population* continues using the most advanced genetic, molecular biology and bioinformatics tools.



**PUBLICATION:** RYR2, PTSS1 and AREG genes are implicated in a Lebanese population-based study of copy number variation in autism. Silva Kourtian, Jihane Soueid, Nadine Makhoul, Simona Ghanem, Sariah Haddad, Joelle Makoukji, and Rose-Mary Boustany (Scientific Reports Nature Publishing Group, 2015, in press)

## 2. And, for the first time, **prevalence of Autism in Lebanon has been determined!**

In Lebanon, no estimate for autism prevalence existed. A cross-sectional study examined the prevalence of Autism Spectrum Disorders (ASD) in toddlers in nurseries in Beirut and Mount-Lebanon. The sample included 998 toddlers (16-48 months old) from 177 nurseries. **ASD prevalence was 1 in 66 children (comparable to US).** Sex ratios were male/female 1: 1.05 contrary to a ratio of 4:1 in the West. **Thus, the total number of children with ASD between 0-4 years in the Beirut and Mount Lebanon areas (based on 2009 population figures) would be 1,157.**

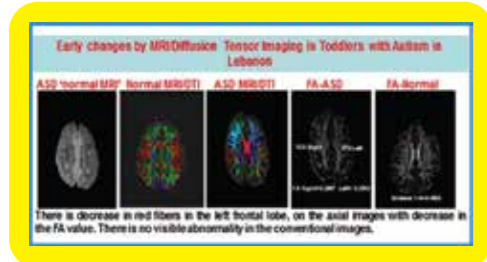
According to the WHO Lebanon Demographics Profile, the population of Lebanon is estimated at 5,882,562 as of July 2013. Hypothetically, this could mean that as many as 22,116 kids could be affected with autism in Lebanon. **Not more than 1,000 actually receive any services...**

*PUBLICATION: Prevalence of Autism Spectrum Disorders in Nurseries in Lebanon: a cross-sectional study. Monique Chaaya, Dahlia Saab, Fadi Maalouf and Rose-Mary Boustany (2015, just published). Journal of Autism and Developmental Disorders 09/2015; DOI:10.1007/s10803-015-2590-7. We are presently extending prevalence studies of ASD to nurseries in the Bekaa/North/South Governorates.*

Generous support from OpenMinds has led to two publications in high profile international journals.

3. A novel MRI technology or Diffusion Tensor Imaging (DTI) shows abnormalities in brains of children with autism, while conventional MRI does not. **White Matter Tract Development in Autistic Toddlers by DTI and Correlation with ongoing therapies.** MariTherese Saade MA BCBA, Ahmad Hammoud MD, Rayan Tutounji PhD, Roula Hourani MD, Rose-Mary Boustany MD.

Abnormalities were seen in 30% of toddlers with ASD. Therapies have provided significant improvement in VB-MAPP measures. This may lead to correction of brain abnormalities laying the groundwork for petitioning for full medical coverage for crucial early intervention.

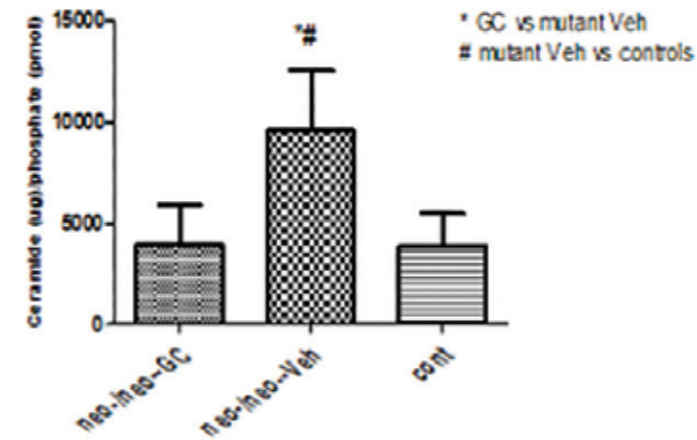


4. New eye tracking study may lead to early and easy detection of autism. **Vision Screening and Visual Tracking in Autism.** Christiane Al-Haddad MD, Karine Ismail, MSc, Rose-Mary Boustany, MD. We plan

to perform eye tracking tests and vision screening using state of the art technology for children diagnosed with autism as well as their siblings (a high risk group) to identify co-existent eye conditions.

5. Is breastfeeding protective to development of autism? Stay tuned... **Breastfeeding and Autistic Disorders: is there an association? A case control study.** Mona Nabulsi MD, Yolla Yousseff MD and Rose-Mary Boustany MD.

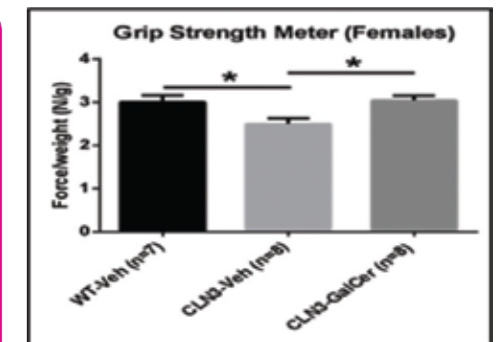
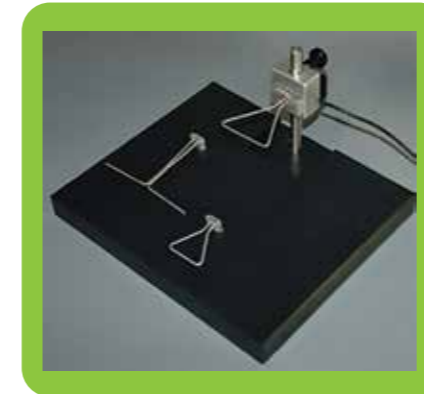
**OTHER GENETIC RESEARCH:** Juvenile Neuronal Ceroid Lipofuscinosis (JNCL/CLN3 disease) affects children leading to blindness, seizures, motor decline and early death. The  $Cln3\Delta ex7/8$  mouse harbors the human mutation and manifests changes consistent with JNCL and is a good model to test therapeutic strategies. Injection of the  $Cln3\Delta ex7/8$  mouse from 8-17 weeks with GalCer reduced subunit C accumulation in brain and organs, and lowered brain ceramide, which leads to neuronal cell death. GalCer also improved locomotor activity in affected mice.



An expanded mouse trial with long-term treatment is underway to assess the impact of GalCer treatment on the disease. This is accomplished by measuring ceramide after GalCer injections in serum and brain, staining brain and organs with subunit C, and other antibody markers for brain inflammation and neuronal death.

Cer levels in homozygous  $Cln3\Delta ex7/8$  mouse brain after exogenous GalCer. High Cer levels were observed in brains of 17-week old vehicle treated homozygous  $Cln3\Delta ex7/8$  mice. GalCer treatment of homozygous  $Cln3\Delta ex7/8$  mice (20 µg daily, 5-17 weeks of age) dropped brain Cer levels to those observed in controls.

The impact of GalCer on behavioral tests comprise wire hanging, grip strength meter, pole climbing, rotarod and T-maze performance.



We showed that exogenous GalCer led to an improvement in the grip strength of mice in both males and females in GalCer-treated versus Veh-treated  $Cln3^{-/-}$  mice. An improvement in the balance and motor coordination was also demonstrated in GalCer-treated  $Cln3\Delta ex7/8$  female mice which performed better than Veh-treated mice on the rotarod test. **These preliminary findings are indicative of the potential use of GalCer as a therapeutic intervention to reverse CLN3 disease progression, in the mouse and ultimately in children with CLN3 disease**

## Spreading the word and raising awareness experientially

**OpenMinds and CARE go live!!** The CARE (Consultant Advocacy for Remedial Education) team, with support from OpenMinds, had an amazing summer filled with fun at a CARE summer camp catering to kids with autism and other special needs ages 9 to 21. The main objective was for a holistic experience in a structured, supportive and positive environment promoting integration of special kids into society. Young adults volunteered at CARE in order to give these special children a fun filled summer experience much, like their regular peers. Aides and special educators attended a 3-day intensive training course administered by professionals. The course covered working with special needs kids and managing their activities, in addition to first aid skills. All participants received certificates of attendance.

OpenMinds supported this wonderful activity and provided for all sports equipment, training program expenses as well as financial aid for some participants. This was a joyous and successful event best described by one of the young volunteers:

*“I've had many nice experiences in life, but I will share with you the most unique, beautiful and the one that opened my eyes the most. Working with CARE has taught me so much. I discovered who kids with special needs actually are. I felt proud to be there for them. While typing I'm listening to a student's favorite songs. Seeing the smile on his face while singing made us forget our worries, egging us to sing along with him. A child with autism, Down syndrome or any kid with special needs does not imply weirdness. These youngsters are the happiest persons around, and they are champions, in spite of life's challenges. Just a little affection turns their frowns upside down into smiles. They have taught us how important it is to love and care.*

*A special shout out to the four students I was responsible for: you guys changed the way I see the world in two months more than what I was able to see in 17 years of living. Spread the news that a child with special needs is not to be ignored. They are not alone. We must open doors for them, and be alongside in this big universe.”*



While in camp the students participated in an array of educational, recreational and social activities covering: social skills, educational and outdoor games, field trips, horseback riding, arts and crafts, recreational skills, swimming, sports, music therapy, cooking, and vocational guidance! To enhance the experience most activities took place in an integrated setting outside the center.

The summer camp finale was a three-day sleep over at a resort in Tyre, which the children and staff greatly enjoyed.

**OpenMinds and all of you have supported Lebanese Youth in the Fight Against Exclusion**

OpenMinds with “Include” Association, the Scouts of Lebanon (SDL) and the Association of Guides of Lebanon (GDL) participated in workshops this October under the title of “Inclu'scout” and “Inclu'guide”. The goal of the workshops was to strengthen the concept of inclusion amongst youth. “Include” believes in the importance of inclusion of kids and young adults with special needs in education, leisure activities and employment. The Association of Scouts of Lebanon (SDL) enables children and young adults to become masters of their own education. The Association of Guides of Lebanon (GDL) encourage girls and young women to develop their full potential as world citizens.

The workshops, made possible by OpenMinds, were directed by Jean Philippe Lacaze and Fady Asmar. Mr. Lacaze, a renowned professional, was flown in from France for training which took place in Beithania, USJ and Notre Dame de Puits, October 24-31. Trainers and supervisors were educated in developing inclusion within the Lebanese scout system, and taught young men and women to manage disability.



**100 scouts were trained. 200 youngsters were hosted.**

OpenMinds is proud to promote its young ambassadors of inclusion in the fight against isolation of special needs kids!

**All Back to School!!**

OpenMinds has been actively lobbying and helping schools embrace sustainable special educational programs and activities in their normal curricula. In October 2014, OpenMinds completely renovated two floors at the Lebanese Evangelical School to create therapy rooms dedicated to functional academic programs geared towards kids with special needs. Such programs allow children to learn practical skills needed in daily life. In October 2015, OpenMinds set up a speech therapy room and a psychomotor therapy room at the Antonine International School (Ajaltoun), to advance skills and facilitate learning. Several workshops took place at the Antonine International School to train therapists and educators in launching special education programs in their schools. In October 2015, OpenMinds earmarked for the Makassed school funds to equip a room needed to promote the instruction of students with learning difficulties. OpenMinds board members continuously identify and visit schools, encouraging them and offering tangible support to start and/or expand special education programs. Such schools have included Jesus and Mary (Rabieh), Sagesse (Brazilia), Antonine Sisters School (Jamhour), Ahlia school (Beirut), Heritage College (Old Airport Road), Cedars High School – Gates (Bauchrieh), Ataya International School (Hadath) and Saint Mary’s Orthodox school (Ras Beirut).

## Life Beyond School...

Providing opportunities for young adults with special needs in the professional domain is a top priority for OpenMinds and all concerned parents. With such staggering numbers of individuals with special needs, employment and productivity in adulthood of such individuals will be paramount to the future success of our communities.

Specialisterne (meaning ‘Specialists’ in Danish) is a company founded by Mr. Thorkil Sonne and is now active in the UK, the USA, Australia and Ireland. It strives for a world where special needs young adults have equal opportunities in the labor market. They hope to secure one million jobs for people with autism and similar challenges through social entrepreneurship, corporate sector engagement and a global change in mind-set. They harness the special talents of people with autism and use them to competitive advantage to secure meaningful employment. Board members had a fruitful and informative Skype meeting with CEO Thorkil Sonne earlier this summer. In doing so OpenMinds has adopted locally what is cutting edge currently in the West.

In 2015, OpenMinds launched a pilot program in coordination with Mr. Ali Hamzeh. Mr. Hamzeh is a special educator in charge of the AUST LEAPS program for individuals with special needs. The intent of the pilot program is for OpenMinds to initiate a channel through which young adults with some formative training can become productive members of society. The program involves close cooperation and documented follow up between AUST and the human resources personnel of companies identified by OpenMinds. OpenMinds is proud to have supported the successful initiation of a young man within the **Batchig and Mayrig** restaurants.



Another was recruited by **Impact BBDO** on a 6 month rolling basis. Both individuals have realized partial financial independence and have gained huge boosts to their self worth, confidence, and overall happiness. Our goals are to increase the number of candidates placed successfully, and to increase the number of interested employers by working closely with Human Resources professionals in the community.



### OpenMinds 2015/2016 Calendar

- AUBMC Special Kids Clinic Team Building Day – December 5, 2015
- AUBMC Special Kids Clinic Christmas Bash – December 12, 2015
- Rare Disease Day – February 28th, 2016
- OpenMinds/AUBMC Special Kids Clinic – Genzyme Special Conference – March 5, 2016
- Workshop for Human Resources: How your company can edge out others through hiring of special talent – Spring 2016
- Autism Month Celebration – April 2016.