





Dear Partners, Sponsors, Donors, Friends and Family,

This has been an event-packed year with new beginnings rearing their head in our big little world of special needs and on the world stage. We are delighted to share with you in this newsletter some of the many achievements and projects that have kept us busy since you last heard from us.

With new beginnings come new possibilities, like the move of the AUBMC Special Kids Clinic to a new space in the spring of 2017! The growth of the clinic and services is bittersweet, because it highlights the tremendous unmet needs of our young population and their families. OpenMinds outreach into schools and the community is taking hold. Our faith and resolve are limitless. With your big-hearted and unwavering support lifting us up, we pledge to continue on our path of service and dedicated commitment to expert clinical care, awareness, education and cutting edge, regionally relevant research into neurodevelopmental and neurogenetic disorders.

It is a time to give thanks to all of you, our benefactors, young patients for their courageous hard work, and our staff and therapists for their dedication and compassion.

A very happy holiday season to all.

On Behalf of OpenMinds board members and the AUBMC Special Kids Clinic,
God Bless you all.

Ghida Rabbat
President, OpenMinds

Rose-Mary Boustany
Director, AUBMC Special Kids Clinic



OpenMinds Board Members celebrating Feb 29, 2016

ITS PARTY TIME!

THE OPENMINDS GALA

We kicked off the year with the always unique OpenMinds' gala dinner at Biel, magically transformed for the night, thanks to our many generous donors, sponsors and partners.

In her message, OpenMinds' president Mrs. Ghida Rabbat urged Lebanese society "to change its perception of persons with special needs, and evolve in the direction of recognizing and accepting them." She highlighted that 10% of Lebanon's population has special needs, and that "these people deserve equal opportunities and an effort by all to facilitate their integration in schools and the labor market to promote their independence as full citizens living in dignity just like all others."

Dr. Rose-Mary Boustany, director of AUBMC Special Kids Clinic, shared the successes, trials and tribulations of OpenMinds and AUBMC Special Kids Clinic since it was established in 2012. She noted that OpenMinds support for scientific and clinical research, medical conferences, diagnostics and treatments for children in need, has been a game-changer. Underscoring the large unmet need, the clinic is busting at the seams and has grown by more than 550%. She stressed the importance to "recognize those who are different as part of us", and that EVERYONE deserves a chance at "health, knowledge, employment and happiness."

Biel was the 'it' place to be on February 29th, 2016. Over 600 prominent individuals from all walks of life came together to celebrate and support our cause. Soprano Tania Kassis belted out the Lebanese National Anthem followed by an exclusive fashion show by Elie Saab, and Nancy Ajram serenaded party goers until the wee hours with EmCee Wissam Hanna presiding over festivities.



Biel Transformed



Elie Saab Fashion Show



Party Time

The gala provides funds crucial for vital research projects, OpenMinds community and education endeavors, medical assistance and training initiatives. Every year research progress promotes leverage at AUBMC and within the community and positions the AUBMC Special Kids Clinic and Neurogenetics Program as a center of excellence for autism and regionally relevant world class genetic research.

EMPOWERING FAMILIES.....

OpenMinds Patient/Family Packages update:

Thanks to our many benefactors the number of special needs kids and their families benefitting from early intervention has exceeded 160 and we still have 2 months to go...

In three years more than \$900,000 have been spent on helping families

to benefit from accurate diagnosis, genetic counseling/prenatal diagnosis, as well as hospitalizations and life-changing early intervention for premature babies, children on the spectrum and many others with neurogenetic and neurodevelopmental disorders.

Giving everyone a Head Start:

There were numerous obstacles facing Ali Khudr, a Syrian refugee from Idlib. Amongst them his refugee status, lack of finance and his two year old daughter Shahd's medical condition: a rare genetic disease called Hurler syndrome which causes facial deformities, stunted development and progressive intellectual disability. Dr. Rose-Mary Boustany successfully lobbied Genzyme, the world's only provider of the enzyme, lysosomal alpha-L-iduronidase, to provide the medicine Shahd needs to halt the progression of her disease. Though the enzyme usually costs \$100,000 per year, it was acquired free of charge through the company's compassionate use program. All hospitalizations to administrate therapy were covered by OpenMinds. Furthermore, care was provided to Nariman's autistic son Nassim in Mount Lebanon, as well as scores of other families. Nariman was able to afford treatment because of OpenMinds. OpenMinds and the AUBMC Special Kids Clinic enables families like Ali's and Nariman's to give their children a head start in life.



Shahd receiving enzyme at AUBMC



CONFERENCE ON TREATABLE LYSOSOMAL STORAGE DISEASES

On September 3, OpenMinds and the AUBMC Special Kids Clinic held a conference entitled “Lysosomal Storage Diseases: The Trek from Patient to Genes and Back” at Issam Fares Hall/AUBMC.

The conference raised awareness about Lysosomal Storage Diseases (LSDs) and their treatment in Lebanon/ Arab World.

LSDs are rare, but not in the Middle East where consanguinity accounts for 16 – 32% of marriages dramatically raising the risk of genetic disorders.

Awareness amongst pediatricians/pediatric neurologists and neurogeneticists, hematologists, cardiologists and nephrologists was heightened. Great visibility provided by Annahar newspaper coverage informed government, insurance companies and the general public about availability and dire need for provision of effective therapies for these disorders that are life-changing. The event was a great success with high caliber international speakers including AUB President Fadlo Khuri, Joseph Muenzer (USA), Arndt Rolfs (Germany), Miguel Abboud, Simona Murko (Tchechoslovakia) and Rose-Mary Boustany.



Conference Backdrop

There is nothing worse for a family than NOT having a diagnosis for their child. What is even worse is giving the parents a diagnosis with no solutions or treatments in sight. This propels many physician-scientists to strive to change this, at least sometimes, through applied research. It had been customary to rely on the West for coming up with solutions. Yet, in this age of genetics and genomics and personalized medicine it is vital to carry out locally relevant research and locally applied solutions for Lebanon and the region with wider implications for all of scientific research. Support for research by OpenMinds, made possible by the generosity of our visionary and benevolent donors has made this a reality.

Translational/clinical research achievements of the Neurogenetics Program and the ASKC clinic:

We established the prevalence of autism in Lebanon as 1:68 with a male to female ratio of 1:1,13. In the US the prevalence is 1:54 with a male to female ratio of 4:1!

Predisposing risk factors for autism in the Lebanese include consanguinity, family history of psychiatric disorders, late birth order, and maternal/fetal complications during pregnancy and at the time of delivery.

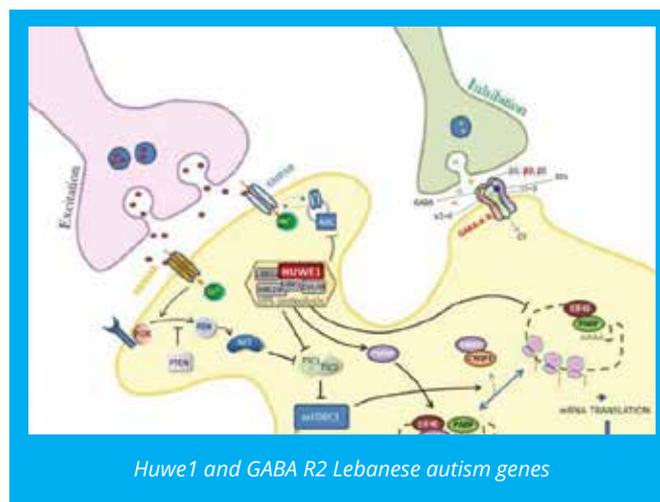
Three novel genetic glitches have been identified in 3/8 families subjected to whole exome sequencing.

1:68

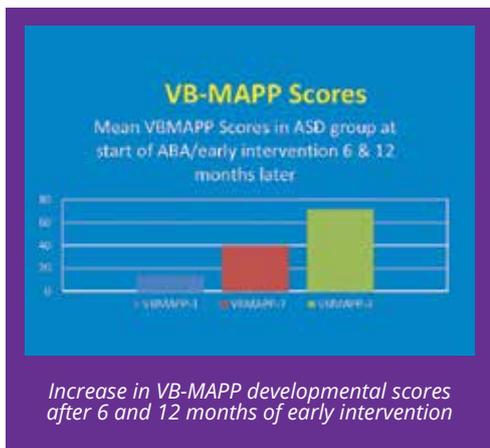
in Lebanon

1:54

in the US

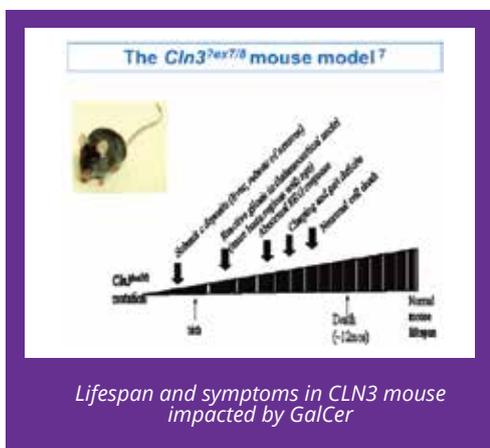
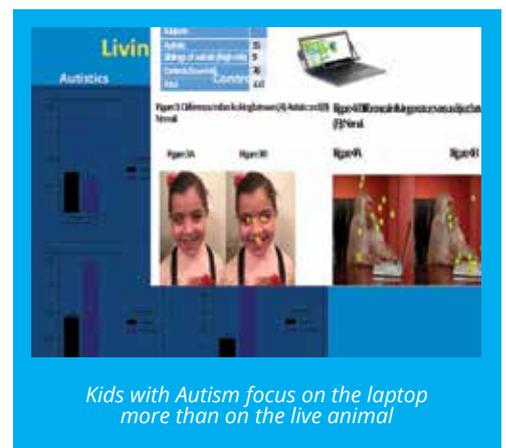


Huwe1 and GABA R2 Lebanese autism genes



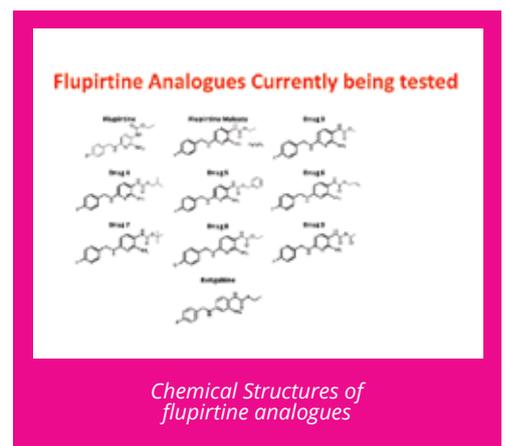
Early intervention including speech, occupational, psychomotor and applied behavior analysis has dramatically improved developmental outcomes in autism and has enhanced brain white matter integrity after 1 year of therapies.

State of the art visual tracking of kids on the spectrum versus normal kids is beginning to show distinctive differences with longer time to focus, less time spent on images, and scattered patterns of visual tracking with focus on inanimate objects versus live objects providing a quick and early diagnostic tool to identify young toddlers and siblings at risk.



A novel treatment, galactosylceramide, specific for a rare neurogenetic disorder (CLN3 disease) patented by Dr. Boustany, AUB and Duke University has been licensed to a US company to bring it to market, after successful treatment of CLN3 disease affected mice.

Nine analogues of a compound (flupirtine) have been tested, three of which promoted survival of a number of cell lines derived from kids with these deadly disorders (CLN1/2/3/5/6/8 disease) of which CLN2 and CLN6 disease are prevalent in Lebanon.



THE ROAD TRAVELLED TO A BETTER FUTURE...

INTEGRATION IN SCHOOLS

Harvard Training Program/Step Up Program.

Two concerned parents, a school principal, three special education coordinators and a university professor set off to Boston this summer to attend a training program at Harvard entitled "Universal Design for Learning: Leading Inclusive Education for All Students" sponsored by OpenMinds and the Lebanese Down Syndrome Association. The course provided means of engagement, presentation, action and expression, addressing diversity of students in the classroom as a means to ensure academic success. It provided application of neurological scientific discoveries to service diverse learners reshaping understanding of learning motivation and using customized teaching/learning via flexible novel technologies. New frontiers were covered as to how advances will change the delivery of classroom materials. National policies impacting teaching and learning and recognition of limitations of "normal" education were addressed highlighting diversity among learners.

Fully engaged OpenMinds board members have been actively lobbying official bodies for legislative and public policy support. More significantly, they have engaged schools to embrace sustainable special education programs and activities in their normal curricula.



Antonine International School awarded OpenMinds special recognition for their support for building an "All children can learn" Inclusion Center on May 13, 2016.

At Sagesse Brazilia, OpenMinds helped build a department which will enable the school to enroll more special needs students. The building opens its doors at the end of 2016.

OpenMinds donated a brand new sensory room for the Makassed School which is already being put to great use.



In October, OpenMinds partnered with Cedar High school by equipping an entire computer lab for students with special needs attending the GATES Program Toward a Happy and Independent Learner!

OpenMinds partnership with Trait D'Union deserves special mention: It is a Resources and Orientation Center established by the Foyer de la Providence and the Institut Européen de Coopération et de Développement. Trait d'Union works in cooperation with the affiliated "Mosaik" school with the aim of assisting mainstream public schools by providing training and support for implementation of inclusive practices involving parents, schools and concerned therapists. OpenMinds will be assisting nine schools in the Saida region. We are extremely excited seeing this new initiative bear fruit!

AUTISM MONTH CELEBRATION



AUBMC Special Kids Clinic bathed in blue

Light it blue event – April Campaign

We lit up the AUBMC Special Kids Clinic blue to celebrate World Autism Awareness Day. The LIGHT IT UP BLUE 2016 campaign organized by OpenMinds and the AUBMC Special Kids Clinic shone joyous and bright lights on autism by illuminating the Pierre Abu Khater building that houses the ASKC clinic in brilliant shades of blue!



Class of 2018, College Notre Dame de Jamhour

Autism Awareness day at College Notre Dame de Jamhour

At Collège Notre-Dame de Jamhour and in collaboration with OpenMinds, all grade 10 students wore blue on April 26. We take this opportunity to thank the class of 2018 and the Collège Notre Dame de Jamhour for their effective awareness campaign.

HO!HO! HO! We celebrated Christmas, 2015 at the AUBMC Special Kids Clinic with seasonal good cheer and games.

"Beirut Vocal Point", our loyal A Capella choir caroled us for the 3rd consecutive year, played with the kids AND donated \$ 1000 to OpenMinds efforts. The morning was chockfull with kids enjoying treats, having a blast with face painting, animal balloons and clowns on stilts. Santa gave out toys and posed with our kids...



Beirut Vocal Point singing Christmas



Merriment of Kids, Therapists and Families



**THE LAST 3 YEARS –
WE COULD NOT HAVE
SURVIVED THEM
WITHOUT YOU!
THANK YOU**

OPENMINDS 2016/2017 CALENDAR

Upcoming events:

- AUBMC Special Kids Clinic 5 year Celebration – 10th December 2016
- AUBMC Special Kids Clinic 2016 Christmas Bash – 10th December 2016
- World Rare Disease Day – 28th February 2017
- OpenMinds Gala – 9th March 2017
- Autism Month Celebration – April 2017



OpenMinds

Located at AUBMC - Special Kids Clinic
Clemenceau St.

Abou Khater Bldg., Ground Fl.

Beirut 1107-2020

Lebanon

Phone: +961 1 350000 ext. 7808 or 5640

Fax: +961 1 750699

www.openmindslebanon.org

info@openmindslebanon.org