

Dear partners & friends,

Since its inception in 2012, OpenMinds continues to positively and significantly impact the lives of thousands of special needs individuals and their families all over Lebanon.

Our efforts not only continue to empower individuals with special needs through the advancement of services in Lebanon, but also shape social behaviors, by shattering crippling taboos, and advancing research into neurodevelopmental disorders at a regional level.

The achievements listed in this newsletter cover the 18 months beginning January 2021. The initiatives have been numerous and the impact on society has been significant. In 2021-2022, our assistance to our community was rebalanced by placing resources in the areas of greatest demand, given the dire situation the country has been in. One must never underestimate the extreme difficulties we are facing as a nation through cycles of political instability, total economic collapse, a catastrophic explosion, not to mention a global pandemic.

Similarly, one must not overlook the extreme passion and drive that our volunteer board members continue to pour into each and every project attained.

We need help to continue helping those who are marginalized, impoverished, and helpless – not because of their disabilities, but because of the lack of opportunity to discover and utilize their many abilities.

**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



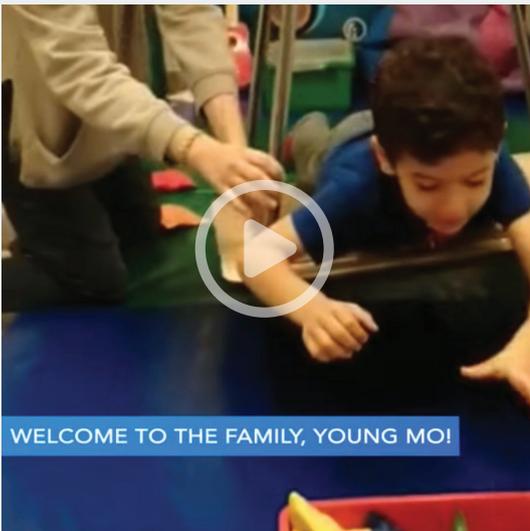
# Clinical Packages at AUBMC Special Kids Clinic

For the ASKC and OpenMinds the aforementioned financial, health and other calamities facing Lebanon have only translated into a larger than ever number of children with special needs requiring diagnosis, management and assistance at all levels.

In 2021, OpenMinds supported 50 new families and 40 recurring families with clinical packages. In 2022 to date, OpenMinds has supported 43 new families and 48 recurring families with clinical packages at the ASKC. From an initial group of 40 families in 2014, we are proud to have assisted over 570 families by mid-2022. The increase in therapy hours provided by the ASKC to children and adolescents increased by >50% from January to August 2021 to 2022.

This has necessitated recruitment of pediatric neurology physicians from two to four highly qualified individuals and a need for additional therapists in all disciplines, which will translate into expansion in space to provide vital services.

## A glimpse into 2 of our success stories



Mohamad Ali



Nabil



# Special Education Scholarships

In 2018, OpenMinds started to offer special education scholarships. The continuous effort and dedication of our partners and donors has allowed us to keep offering more than double the amount of scholarships every year. In the 2021-2022 academic year, we were able to offer 174 scholarships in 10 schools across Lebanon. The 2022-2023 academic year promises to reach even more students, as the demand intensifies significantly.



## List of schools

- Antonine International School
- Beirut Baptist School
- Cedars High School
- Collège Notre Dame des Sœurs Antonines Hazmieh Jamhour
- Khaled bin Al Waleed Al Horch Makassed School
- Lebanon Evangelical School for Boys and Girls
- Lycee Khadija al Kobra
- Sagesse Brazilia School
- Shouf National College
- Step Together Association

# Research at AUBMC Special Kids Clinic

We also continue to speak for those who cannot, by our social, national and international scientific and media presence. OpenMinds and the ASKC represented by Mrs. Suha Beyhum, Mrs. Rima Faddoul and Dr. Rose-Mary Boustany, proudly hosted Special Envoy to US President J. Biden, Ms. Sara Minkara (Special Advisor on International Disability Rights) at the ASKC on March 18 2022.

Examples from late 2021 and 2022 are:

**Sep 12, '21. PODCAST: Professors at Work** (Rami Khoury): She leads genes, cells, and molecules into battle against rare childhood diseases. American University of Beirut: Rose-Mary Boustany.  
[she-leads-genes-cells-and-molecules-into-battle-against-rare.mp3](#)

**March 9, '22.** Faculty of Health Sciences-AUB: **Autism in Lebanon: 2022**

**March 11, '22. THE RESEARCHER.** LBC. Season 2-Episode 5 (**autism**).  
S Saab, J Makoukji, K Kanaan, G Hassan, N Makhoul, J Soueid,  
P Trippier, R-M. Boustany.



**Flupirtine Derivatives as Treatment for CLN6 Disease** (Poster-May 9/10 '22). Research of the Future: Challenges and Opportunities (AUB-6th CRSL Research Conference. Kamal Shair Auditorium AUB).

Sara Saab, Joelle Makoukji, Karen Kanaan, Rose-Mary Boustany Batten Disease Support and Research Association Virtual Meeting U.S.A: **Phenotyping of the Cln6 or nclf mouse model: Retinal, behavioral and molecular aspects. July 9th 2022.**

Jihane Soueid, Lara Al-Bazzal, Rose-Mary Boustany. **Novel Autism Genes and Perturbed Proteostasis. AUB-6th CRSL Research Conference). May 10, 2022.** Research of the Future: Challenges and Opportunities (AUB-6th CRSL Research Conference. Kamal Shair Auditorium).

*Thanks to crucial funding provided by OpenMinds to the ASKC and the Neurogenetics unit academic productivity has soared with international publications increasing to 116 from 68.*

*Progress that translates to help for complex neurodevelopmental conditions, like autism, takes time, effort and funding. We provide care for more than 1000 families with children with autism at the ASKC. We began in 2010 by collecting blood samples from 41 families, establishing prevalence, publishing on prevalence, risk factors and positive impact of crucial early intervention on the brain and clinical outcome in autism. We have now identified 4 novel genetic defects causing autism.*

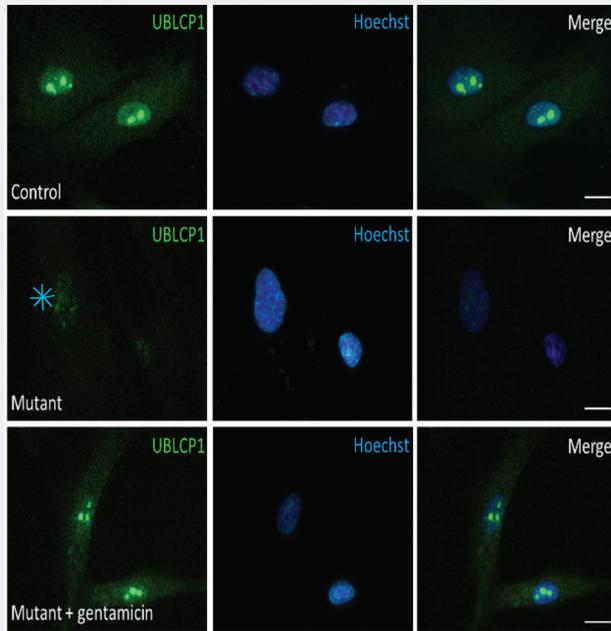
**For one of those defects, 12 years later, we have a handle on a possible therapy**

A Lebanese family with autism or ASD has a defect in the **UBLCP1 gene** consisting of a **premature stop** resulting in a shortened and less stable UBLCP1 protein. The normal function of the UBLCP1 protein is to dampen protein cell breakdown. When UBLCP1 is diminished or non-functional, protein breakdown becomes out of control resulting in cell damage. Gentamycin or the safer ataluren are drugs that can trick cells into reading across the premature stop helping them increase amount of UBLCP1 protein and restore function.



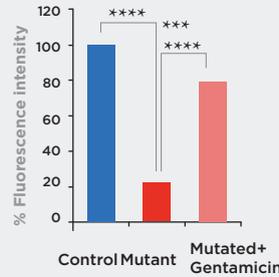
UBLC1 gene with premature stop

a.



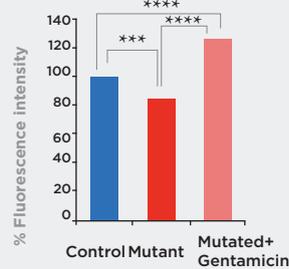
b.

UBLC1 nuclear expression

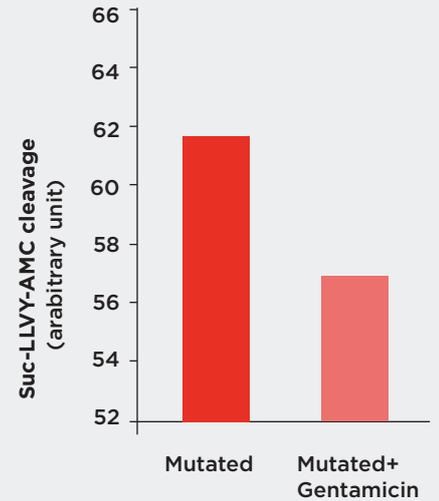


b.

UBLC1 cytoplasmic protein expression



d.



Amount of UBLC1 and function are restored in skin cells from the ASD patient after treatment with gentamicin. (a) Normal skin cell (upper panel) and cells with UBLC1 ASD mutation (middle panels) treated with gentamicin (lower panels), immune-stained for UBLC1 (green) and nucleus dye (blue). (b and c) UBLC1 nuclear and cytoplasmic protein expression are low in cells from the ASD patient. Note: restoration of UBLC1 protein after gentamicin treatment. (d.) UBLC1 function is restored in mutant/ ASD cells by gentamicin. A desired decrease in proteasome activity occurs in cells from ASD patient after treatment.

# Integration

Despite the difficult times we are facing, we were able to successfully contribute to the launching of a new section at Makassed Lycee Khadija al Kobra, Makassed Learning Abilities center in November 2021. All resources were provided by OpenMinds to help with speech and psychomotor therapies. An opening ceremony was held on March 29, 2022, in the presence of the French Ambassador to Lebanon, Ms. Anne Grillo. Additionally, we continued to develop from our previous collaboration called "I Can Work" with Step Together to the "I Can Be Productive" workshop for the 2021- 2022 academic year that helps young adults participate in various workshops and learn important skills.



Makassed Lycée Khadija al Kobra



Inauguration event



Step Together Association - I Can Be Productive collaboration -2021-2022

## Autism Campaigns April 2021 -2022



In 2021, we launched a highly successful Autism Awareness campaign which was aired on MTV and LBC throughout the month of April. The campaign drew attention to the communication challenges and frustrations experienced by individuals with autism, by highlighting the online communication glitches experienced, at the time, by the whole world!



In 2022, as Lebanon continued to struggle, we decided to mark Autism Awareness month with a campaign that would illustrate visually how the lives of individuals with autism were turned upside down. 65 social media influencers took part in our campaign and flipped their images to affect a visual presentation of a world turned upside down. Similarly, on April 2nd, World Autism Day, MTV inverted the screen of the evening news in order to cause its audiences to be initially surprised, and to give thought to our message.

# World Autism Acceptance Month

“

Awareness is knowing someone has autism. Acceptance is when you include them in your activities to develop in that community and get that sense of connection to other people

”

CHRISTOPHER BANKS  
President and CEO  
of the Autism Society of America

## Collaborations

In an effort to increase awareness and raise more funds, OpenMinds successfully collaborated with local and international F&B outlets. Funds were successfully raised through generous donation programs and donation matching. Thank you to Ilili restaurants in NYC and in DC, Zata in London, and ABC right here in the motherland. ❤️

### ILILI NYC



### ILILI DC



### ZATA LONDON



### ABC DBAYEH



## Awareness



### Expo 2020:

On January 18 2022, The Lebanese Pavilion at Expo 2020 generously offered to help us raise awareness for OpenMinds for four consecutive days. A launching event was held with a presentation on OpenMinds and items produced in collaboration with Sarah's Bag were sold at the Lebanese concept store until March 2022. We would like to take this opportunity to thank The Lebanese Pavilion for giving us a platform to have our voice heard at Expo 2020.

## Collaborations



Following the great success of our collaboration with Sarah's Bag, we partnered with various local businesses to sell even more of our branded tote bags and pouches. Sales were made possible through Toters and Librairie Antoine (where they continue to be sold), and also at Exhale and The Core (until August 2022). A genuine and heartfelt thank you to Toters, Librairie Antoine, Exhale, and The Core for your generous assistance.

## Donation Boxes

### Ginette



### AZIZ



### Villeroy & bosche Downtown branch



### EMAK



This year, we collaborated with various businesses that believe in giving back to the community. Thank you Ginette, Aziz, Villeroy & Boch and Emak for accepting to have our donation boxes on your counters! Every donation counts.

## OpenMinds At A glance...

In a very brief summary, we have raised over:

**\$10.5 Million**



to date.

Offered

**347 Scholarships**



to special needs students; with many more to come for the 2022 - 2023 academic year.

Organized

**19 Community Initiatives**



including social and educational events, seminars, TV and social media campaigns, across all levels of Lebanese society, to encourage inclusion in society, education, and employment at all levels.

World-class genetic research in neurodevelopmental disorders at AUBMC resulting in:

**50 Publications**



in international journals.



**1** Licensed patent.

**1** Patent filed.

Provided over

**573 Families**



with treatment packages at ASKC.

Rehabilitated and assisted

**26 Schools**



all over Lebanon in developing their special needs programs to promote integration within their regular school curricula.

Joined forces and created

**5 Major Collaborations**



with other NGOs on various projects.

Awarded

**6 BCBAs student scholarships**



to increase the availability of internationally certified professionals locally.