



Dear OpenMinds Community,

In these unprecedented times of extreme challenge we all face, particularly in Lebanon, we continue to grasp at slivers of hope, keeping in sight, the silver lining in the clouds. This propels us forward.

Our partners, donors and friends are the hope and power that drives and enables us to thrust forever forward with our mission. This was an exceptionally difficult year.

Like all, we confronted turmoil, economic challenges in Lebanon and worldwide, and an unparalleled and overarching global pandemic.

Despite these taxing times, we helped 65 new families and continued to assist another 43 with medical and therapy packages at the AUBMC Special Kids Clinic, covered 85 scholarships for special needs students mainstreamed in regular schools and aided by OpenMinds in the past, and, against all odds, continued to support and fund ongoing clinical and basic research.

In this newsletter we share with you achievements of OpenMinds for the year 2020.

Whatever the future holds, we remain determined to keep our mission alive by addressing the plight and difficulties faced by Special Needs individuals in Lebanon, now, in 2021 and the future.

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Clinical Packages & Research at AUBMC



OpenMinds supports 5655 special needs services at the AUBMC SPECIAL KIDS CLINIC (ASKC)....

OpenMinds funds advances in local clinical/basic science of special needs at the NEUROGENETICS (NG lab) at AUBMC...



Nothing has dampened the spirits of the ASKC or NG teams at AUBMC.



In spite of restricted access, our doors stayed open, and we have soldiered on.

ASKC OpenMinds (OM) Clinical Packages

ASKC-OpenMinds Sponsored Visits By Procedure			
OpenMinds & Total ASKC visits in 2020 by type			
NEW Patients/65 Returning Patients/43 OM Patients: 108		Jan 1 2020- 31/12/2020	
Procedure	OpenMinds numbers	% of Total	Total ASKC numbers
Applied Behavior Analysis Sessions	3,766	33%	
ABA Training	314	28%	
Physical Therapy	289	21%	
Occupational Therapy	391	34%	
Psychomotor Therapy	397	47%	
Speech Therapy	318	33%	
Feeding Therapy	58	19%	
ADOS	12	38%	
VB-MAPP	29	41%	
Initial non-ABA	81	25%	
Doctor Clinic Visits	200	2%	
Audiometry	11	30%	
Genetic Tests	27	30%	
EEGs	13	30%	
Lab Tests	30	30%	
Total	5,655	38.8%	14,578

Success Stories





ASKC/Neurogenetics Research

**Publications in 2020/early '21 were 15, exceeding all averages.
Grant applications submitted based on OM funded work number 9!**

Research Highlights

- ✓ Two novel Lebanese autism genes identified, **UBLCP1** and **UBR4**.
- ✓ **'RitaT'**, a new and rapid screening tool for autism was validated in Lebanon and is translated into Arabic.
- ✓ Negative impact of screen time on severity of autism in the Lebanese is published.
- ✓ Effectiveness of flupirtine to **treat** mice affected with **CLN3 disease** with sex differences defined is in print.
- ✓ Eye tracking and gender specificity in autism uncovered and published.
- ✓ Protective impact of breast feeding on autism in Lebanon has been shown.
- ✓ **Hot of the presses...**
The CLN6 batten disease variant prevalent in Lebanon is being investigated in the **Cln6^{nclf}** mouse model...

Visual Cliff test

28-week old male Cln6^{nclf} mice (n=3) could not discriminate between a safe zone and crossing over the cliff to the unsafe zone, spending equal time due to a significant loss in vision. Cln6^{nclf} male mice spent more time over the cliff vs. age matched normal males (black bars) and less time in the safe zone (grey bars) (unpublished).

Fig 1a.

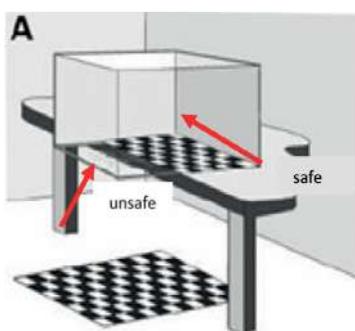
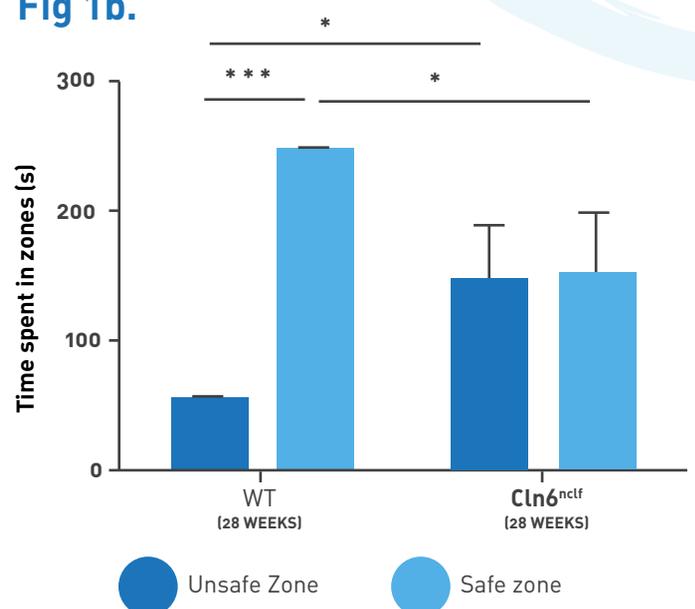


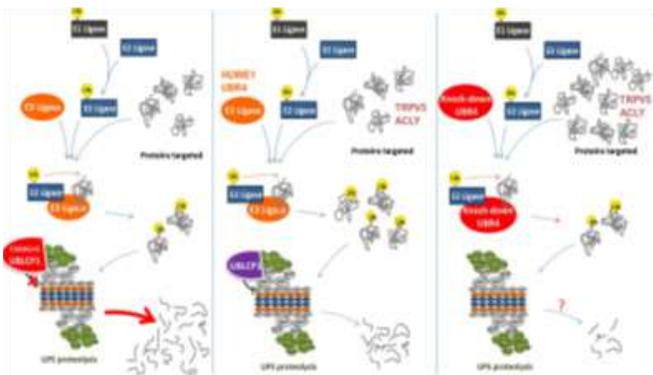
Fig 1b.





The 2 autism genes identified affect vital protein degradation machinery in the cell, but differently. It turns out that defective UBLCP1 gene can rescue and may be developed to treat defective UBR4.

Fig 2. Both UBLCP1/UBR4p impact proteolysis or protein breakdown



Central panel

Normal UBR4p is an E3 ligase. UBR4p substrates TRPV5p & ACLYp are linked to ASD. Normal UBLCP1p binds Rpn1p & dephosphorylates Rpt1p & inhibits proteasome assembly and activity.

Left panel

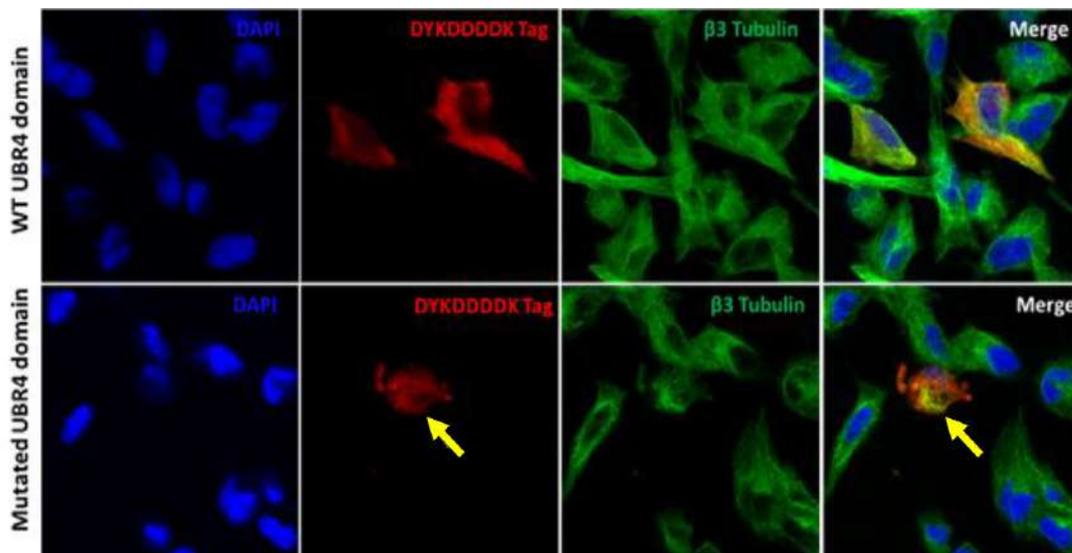
Mutated UBLCP1 does not lead to increased proteolytic cleavage.

Right panel

Mutant UBR4 impacts proteasome degradation via protein recognition/Ub-transfer from E2-ligase to proteins & targets them for degradation ↓Ub- proteins & ↑TRPV5p & ↑ACLYp.

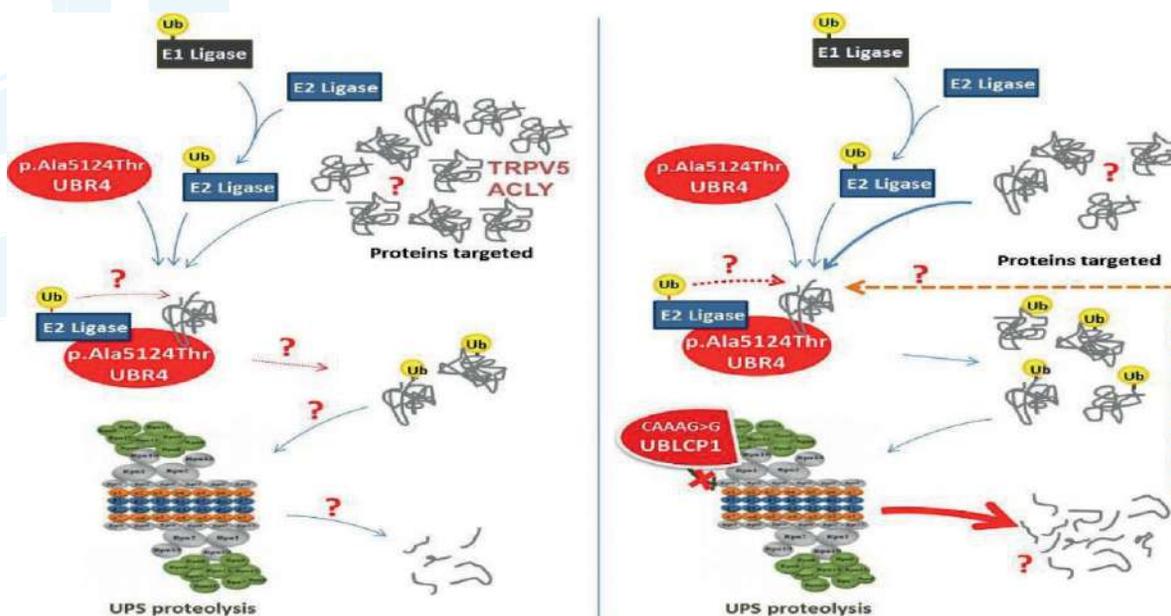


Fig 3. Mutated UBR4p results in cell microtubule destabilization & cell disruption



Cells stained with antibodies to β 3-tubulin of neuronal cells with UBR4 tag (red) and β 3 tubulin (green). Cells over-expressing WT or normal fragment exhibit a tubular pattern (upper panel) BUT a diffuse pattern lacking normal elongated cells in cells expressing mutant UBR4 domain fragment (lower panel). Yellow arrows point to cells with mutant UBR4 causing microtubule destabilization & cell disruption

Fig 4. Mutated UBLCP1p as a potential strategy to treat mutant UBR4



Left: UBR4 mutation leads to reduced protein degradation, and affects protein recognition/UB transfer from E2-ligase to targeted proteins, OR directly targets proteins for degradation. This causes accumulation of proteins. Right: Expressing mutant UBLCP1 rescues mutant UBR4 by \uparrow proteolysis (red arrow) & \uparrow UBR4p activity (dashed orange) & \uparrow Ub-protein levels.



Scholarships Awarded 2020-2021



For the 2020 - 2021 academic year, OpenMinds awarded 85 students scholarships in 9 schools. We increased the number of scholarships to match the increasing demand during these difficult and trying times.

Students were selected based on their financial and educational needs. As in 2019-2020, the schools were chosen from those that OpenMinds has assisted and collaborated with in the past to ensure success.

The total number of scholarships awarded since inception of this program in 2018 is 173.

The list of Schools for the 2020-2021 academic year are the following:

- Shouf National College
- Cedars High School
- Lebanon Evangelical School for Boys and Girls
- Khaled bin Al Waleed Al Horch Makassed School
- Beirut Baptist School
- Collège Notre Dame des Sœurs Antonine Hazmieh Jamhour
- Antonine International School

Scholarships awarded | Testimonials





Employment Collaboration



Seeking employment as an adult with special needs is a daunting challenge. For the fourth consecutive year, The 'I Can Work' program, developed by Step Together Association and funded by OpenMinds integrates students with special needs in actual workplaces in the community, under the supervision of a personal coach and coordinator. During the first academic trimester, young adults focused on two themes: "Working at the Library" and "Working at the Bakery".

Certain adaptations for online instruction were implemented within the programs as required.



“We Shall Continue” Auction



Every single brushstroke is unique and precious just like our special needs children. These incredible art pieces were generously donated by great artists and friends. This auction entailed NO added fees or commissions -Every single dollar raised goes towards helping special children live better lives with the same dignity we ALL deserve.

In collaboration with artscoops.com/auctions/we-shall-continue , nadaboulosauction.com and M Square Gallery



We Shall Continue



Donation Campaigns



During 2020, OpenMinds launched two donation campaigns one during World Autism Month and one at the end of the year. OpenMinds strives to raise awareness of Special Needs Children in Lebanon.

