



OPENMINDS FUND – AUBMC SPECIAL KIDS CLINIC

www.openmindslebanon.org  
<https://www.facebook.com/openmindslebanon.org>  
 +961 1 350000 - ext. 7808



## NEWSLETTER 1, SUMMER 2014



Dear Friends,

OpenMinds is a fund established by concerned parents and their friends to support the AUBMC Special Kids Clinic (ASKC) and the affiliated Neurogenetics program while also aiming to raise awareness for neurodevelopmental disabilities and genetic disorders.

The ASKC is a unique center offering multi-disciplinary medical and treatment services to children with special needs.

ASKC has already provided services to hundreds of families with children affected with autism, other neurodevelopmental disorders, cerebral palsy, genetic disorders and congenital malformations.

Thanks to the support of our partners, sponsors and friends we have been able to inch closer to very important goals:

- 1- Empowering and supporting families in need.
- 2- Conducting much needed research.
- 3- Raising awareness and promoting integration of kids and adults with neurodevelopmental disabilities and neurogenetic disorders in our community.

We would like to share with you the progress achieved in four short months primarily thanks to your generosity and support.

On behalf of OpenMinds and the ASKC. Thank You!!!

**OpenMinds President**

Ghida Rabbat

**ASKC/Neurogenetics Program Director**

Rose-Mary Boustany, MD

### Partners





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### Patient Packages

**Empowering families:** We have so far helped eighteen families with children in need of medical care, hospitalization, sophisticated genetic tests and crucial therapies. Thanks to you we hope to assist many more!



### Advancing research into Neurodevelopmental Disabilities

- **The pursuit of autism susceptibility genes** in the Lebanese population has already unearthed three genes that are currently being validated - we are confident of finding other genes. We are truly excited about these findings as it will simplify diagnosis of autism in Lebanese kids, allowing accurate informed genetic counseling for families. This also paves the way for ultimately devising novel targeted treatments.
- **How common is autism in Lebanon?** No figures currently exist – Together with graduate student Ms. Dahlia Saab and Professor Monique Chaaya from the Faculty of Health Sciences (formerly Public Health) we are screening toddlers attending nurseries 18 months – 3 years of age. We have collected information on 660 infants so far with a goal to collect up to 1200, before a statistically significant analysis of prevalence can be completed. Preliminary results indicate a high prevalence in Lebanon.
- **Are there early markers for autism by MRI?** A novel technology in imaging called diffusion tensor imaging (DTI) allows visualization of connections in the brain. We are investigating whether young autistics have white matter abnormalities in the brain and whether these subside after therapies.
- **Can we cure a rare neurogenetic disorder called CLN3 disease** by injecting a fat attached to a sugar called galactosylceramide? We have preliminary evidence in a mouse model for the human disease of improvement in brain pathology and behavior. We are now embarking on a long term mouse trial which will pave the way towards an actual human trial.



**Dr. Jihane Soueid working on identification of Lebanese autism genes**



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### Awareness

- **The OpenMinds coming out party:** On February 5 at the One raised awareness for special needs in a big way using messages on large screens and live testimonies from parents and board members. Good food, dancing, a fashion show, an auction and gifts were just the icing on the cake.
- **Raising Awareness for Autism:** In conjunction with World Autism Month 2014 in April, we distributed fortune cookies with different messages to Grade 6, 7, and 8 in six different schools as well as to staff and families on the Pediatric ward at AUBMC (6 North). Messages were read out loud by students to their classmates.

### Upcoming Events...

- **Conference:** On Friday November 28, 2014 we will host a conference entitled **Special Kids Transitioning to Adults** at Issam Fares Hall at AUBMC with speakers from England, the United States of America and Lebanon: Valerie Paradiz, Global Autism Initiative, USA; Declan Murphy, Kings College, UK; Ali Hamzeh, AUST, Lebanon; Reem Moawad, FISTA, Lebanon; and Rana Sawaya, CARE Lebanon.
- **Movie Festival:** We will be at the movies from Friday October 24 until Tuesday October 28 at Centre Sofil, 2014. **“Special People at the Movies”** will be a unique event raising awareness using a medium that has touched all our hearts. We will share with the public outstanding and powerful landmark films dealing with autism, intellectual disabilities and genetic diseases.
- **Integration:** We are planning to enhance a designed space within the Lebanese Evangelical School by renovating it. The goal is creation of four functional academic program classrooms (FAP) for special needs kids ages 12 – 18 years allowing full integration into a normal school with side by side education of typical and special needs children. Our ultimate goals are that this program will become the prototype for other schools to follow and for the government to adopt this and provide support.



### Partners





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WE ARE PLEASED TO HOST  
**"SPECIAL PEOPLE AT THE MOVIES"**  
 FILM FESTIVAL  
 WHEN : FRIDAY OCTOBER 24TH - TUESDAY OCTOBER 28TH  
 WHERE : AT CINEMA EMPIRE SOFIL

Partners:

