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Graduation Day!

As parents we wait for this moment! We wish for this moment! A time when we can sit back, reflect and remark on the path travelled and marvel at what comes next. They did it! We did it! As Dr. Seuss appropriately wrote... "You have brains in your head. You have feet in your shoes. You can steer yourself any direction you choose. You're on your own. And you know what you know. And YOU are the one who'll decide where to go..." - Oh the Places You Will Go

Yes, this is the path. This should be the path. Until it isn't! Graduation! A time of celebration and reflection. One of the most exciting times between a parent and a child. Both looking so forward to this moment when everything they had worked so hard to accomplish is celebrated. Almost two decades have been spent in preparation to be equipped to fly from the nest. If we did our job right

our children have been prepped with the key ingredients for success: curiosity, knowledge, resilience, independence, honesty, empathy, an open mind set, grit and compassion.

This is what happens and should happen. Except when it doesn't!

Our son Jacob has Canavan Disease, a progressive and fatal neurodegenerative illness which has slowly taken away his ability to see, move, speak and even feed by mouth. He is completely dependent on us and we have been dependent on the schools and community that have embraced him for sixteen out of his twenty-one years. This past June Jacob graduated! He was dismissed from a school where he had been loved, nurtured, and cared for. This should be something we as parents looked forward to, but instead, we were petrified. What happens when our children can't meet the criteria that sets them up for success in the world after graduation?

What can parents do when there is not a life after graduation? Especially for the fighters out there. Jacob has fought every day of his life. He has made it to the age of 21, he is ready for more. But, more isn't always available. And, he is not alone. In fact, the Ombudsman Report, an investigation into the crisis involving adults with developmental disabilities, called "Nowhere to Turn" states there are over 62,000 adults in Ontario with developmental disabilities.

In this 182 page report we learn.... "Unfortunately, despite the government's recent efforts, there remain individuals on the margins, living with profound and complex disabilities and faced with extreme circumstances. When they reach a crisis point, service gaps often leave them and their families without any real choice, and dependent on a system unresponsive to their needs. Without significant additional reform, many uniquely vulnerable people will continue to be lost in the system and experience harm because of inadequate supports and services."

The report strongly criticizes the confusing array of networks that are simply impossible to navigate when it comes to adults who are medically fragile or severely developmentally delayed.





So what happened? Why is this such a problem and what are parents to do?

Through medical advances and breakthroughs, children with severe disabilities are living longer, way past their original prognosis, but support systems and resources have not caught up. What is waiting are gigantic wait lists for small satellite day programs accompanied by massive fee for service costs.

The Ombudsman made it clear that the decades of delay and the resulting frustration and depression that ensued, have left a broken system and parents in deep crisis.

It is so desperate that some families having reached the breaking point and have simply given up, relinquishing care of their adult child to the province.

So here we are. Jacob, our now twenty-one-year-old miracle boy has graduated, and of course we are proud, even overjoyed. But truly here's what went on in my head while we were trying to navigate our way? What next? What are we going to do? What is Jacob going to do?

We have always been a pro active family, always supporting Jacob's needs, listening to him and following his lead. Now we were confused and scared. We want the best for him, but what we feel is best isn't always available.

Through research I have found a few wonderful organizations out there trying desperately to help solve this problem - Reena, Variety Village, Muki Baum, DANI, LUSO, Harmony Place and Easter Seals just to name a few. There are currently others in the works. All of these organizations fit specific criteria that cater to various needs.

A group of frustrated and eager parents launched POST 21, a day program for young adults with severe medical and complex needs. Set in Etobicoke at a congregated public-school setting, this pilot program will stage a home away from home. A safe, nurturing and stimulating environment to gather with friends and community. With this pilot project in place, hopefully it can help to address the crisis facing so many families today.

Just because our children have graduated, shouldn't mean that their lives have ended. Graduation should be the beginning of something new, something exciting, something spectacular and something to look forward to.

Change must happen so there is Somewhere to Turn.

Since this article was written, Jacob has found Harmony Place, a day program that he attends on a daily basis. Still, the crisis remains for so many and we are dedicated to helping others.

Save the Date

22

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Congratulations Ellen!



ELLEN SCHWARTZ

*Brilliant
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**2018
PHILANTHROPIST
OF THE YEAR
AWARD**

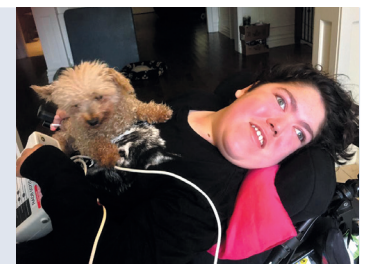
The nominee has actively promoted the welfare of others, vis-a-vis the generous donation of money to good causes. The nominee has received recognition for her efforts in raising awareness to her various platforms.

Ellen Schwartz is an elementary school teacher, community leader, author, public speaker and advocate for research awareness and screening for neurodegenerative diseases. As the Founder of Project Give Back, she links her decades of teaching together with her personal passion for charitable causes. She is also the Co-Founder of Jacob's Ladder. Since its inception, Jacob's Ladder has raised over three million dollars towards research, education and awareness on neurodegenerative illnesses.

READ MORE AT: WWW.BRILLIANTMINDEDWOMEN.COM
To donate, visit www.BrilliantMindedWomen.com

Update on Jacob Trossman

Jacob is happily settled into his second year at Lawrence Park Collegiate. Although his health is still precarious and each day presents its own challenges, Jacob is participating in as many outings and activities as his family and nurses can plan. This past summer he was a regular attendee at the Toronto Zoo, various street and community festivals and a couple of rock concerts. He is always up for a party and manages to summon the stamina to take part in new adventures. Thank you for your continued support and interest in Jacob's accomplishments.



Now there are 2 great ways to support Jacob's Ladder



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The Jacob's Ladder Norman Saunders International Research Prize

In the year 2000 Jacob's Ladder began an auspicious International Research Prize project. This prize, awarded to one outstanding researcher from around the world each year, has provided an opportunity for us to honour each of them for their accomplishments and also to afford them an opportunity to share their remarkable work with physicians and researchers in the fields of genetics and neurological diseases here in our own city.

From the very beginning the Hospital for Sick Children joined with us to create a panel to recommend and invite the world's best to come to Toronto to accept this award. This project was unanimously well received from the onset and to date 15 outstanding candidates have attended. We again congratulate all previous award recipients who have shown outstanding dedication in the field of genetics:

Huda Zoghbi M.D. (2000) Baylor College, Houston, Texas
Evan Snyder, M.D., Ph.D. (2001) Sanford-Burnham Medical Research Institute, La Jolla, California
Anthony Monaco M.D., Ph.D. (2002) University of Oxford, Oxford, England
Gregory Grabowski Ph.D. (2003) Cincinnati Children's Hospital, Cincinnati, Ohio
Salvator DiMauro M.D. (2004) Columbia University, New York City, New York
Hugo Moser M.D. (2005) John Hopkins University, Baltimore, Maryland
Eric Shoubridge Ph.D. (2006) McGill University, Montreal, Quebec
Charles R. Scriver CC GOQ FRSC FRS (2007) McGill University, Montreal, Quebec
Stephen T. Warren Ph.D, FACMG (2008) Emory University, Atlanta, Georgia
Charles Thornton Ph.D, MBA (2009) University of Maryland, Maryland
Brian Robinson Ph.D. (2011) The Hospital for Sick Children, Toronto, Ontario
Cornelius Jakobs Ph.D. (2013) VU Medical Centre, Amsterdam, The Netherlands
Berge Minassian M.D. (2014) University of Toronto, Toronto, Ontario
Adrian Bird CBE FRS, FRSE (2015) University of Edinburgh, Edinburgh, Scotland

Mustafa Sahin M.D. PhD (2017) Harvard Medical School, Cambridge, Massachusetts

In March 2007 Dr. Norman Saunders, Jacob's beloved paediatrician, passed away. To honour this incredible and incredibly important person in Jacob's life the International Research Prize which he helped create was lovingly renamed The Jacob's Ladder Norman Saunders International Research Prize.

On June 12th, 2019 we look forward to welcoming **Fatima Bosch** to speak at Grand Rounds at The Hospital for Sick Children. Fatima Bosch is a full Professor of Molecular Biology and Director of the Center of Animal Biotechnology and Gene Therapy at the Universitat Autònoma Barcelona. Professor Bosch is a Pharmacist (1980) and PhD in Biochemistry (1985) by the University of Barcelona and has conducted post-doctoral studies at Vanderbilt University (1985), Case Western Reserve University (1988-1990), and NCI-Frederick Cancer Research and Development Center (1991). She has been granted numerous awards for her accomplishments in her field during the course of her career and is also a member of the Gene Doping Expert Group of the World Anti-Doping Agency (2013-present).



Her research focuses on studying the pathophysiological causes of diabetes mellitus using transgenic animal models and developing gene therapy approaches to this disease by in vivo genetic manipulation of tissues using non-viral and viral vectors. Recently, she has applied her know-how on gene transfer technologies to the development of gene therapies for inherited metabolic disorders such as Mucopolysaccharidoses.



Our Support for Research and Sick Kids Continues!

For 100 years, scientists have used the humble fruit fly, *Drosophila melanogaster*, to advance knowledge of human disease. In fact, fruit flies have been behind five Nobel Prizes.

At SickKids, Dr. Gabrielle Boulianne's lab has used fruit flies for close to three decades to investigate human development and neurodegeneration. As we reported last year, Jacob's Ladder has helped fund this important research—for a project exploring the causes of rare neurodegenerative disorders that stem from mutations in a single, poorly understood gene called PLA2G6.

Our support helped Dr. Boulianne's lab develop a new fruit fly model and demonstrate its effectiveness as a tool to understand PLA2G6 mutations in humans. Next, the lab will use different lines of the model to probe how

specific mutations lead to different neurodegenerative disorders—aiming to identify target genes and molecules that could lead to new therapies that slow disease progression and improve quality of life for patients with these and other forms of neurodegeneration.



Heather Levine, a prominent Toronto artist has created 3 unique designs for our special all occasion cards. You can order individual cards with your personalized message through our office or now also through our new secure on-line server Canada Helps. Blank cards are also available in sets of 12 for \$60. A charitable receipt is provided for 100% of your donation.

Please call our office at 416-485-0078 or order through www.jacobsladder.ca

phi·lan·thro·py

Merriam-Webster defines philanthropy as an act or gift done or made for humanitarian purposes. By receiving this newsletter, you, someone close to you, or a company you work for, has contributed to Jacob's Ladder in one way or another. In effect, you have been philanthropic.

Jacob's Ladder was formed to accomplish some lofty goals, and along the way, many of them have been achieved, while others have required some heavy lifting and are still underway. Some of the ventures have an ongoing nature to them, and they continue on an annual basis. Your philanthropic gifts have allowed this to happen and continue to support the programs in place. Without them, Jacob's Ladder would cease to exist. However, it hasn't always been about achieving milestones, somewhere along the journey, we evolved.

Early on, almost divinely, Jacob's Ladder became something more than just an opportunity to give back. It became a comfortable vessel for our community to share with the next generation (and beyond) the importance and joys of giving back; of thinking in a benevolent way. In the last 21 years (we can't believe it has been that long), our community has rallied around Jacob's Ladder in a way that is nothing less than remarkable. Remarkable yes, in that we have raised millions of dollars and accomplished significant goals, but equally important has been the ripple effect we see on a daily basis.

We should have seen this wave of community engagement

coming, however we were just so grateful for the support it didn't occur to us. In fact, our first fundraiser wasn't done by us at all; a local Starbucks heard about our story and jumped in to kick start our growth. From there it was golf tournaments, auctions, and movie nights, all the while developing awareness and building the foundation for what we would become. A community philanthropic organization. Our Family Fun Days, Jake's Gigantic Gives and Jake's Jams set the course for how we would travel within our community. Working with families on a multigenerational level to create an environment where everyone, at all levels, could participate and give back became the goal right alongside raising funds to support our objectives. Even now, a month doesn't go by where we don't bump into a young adult reminding us that they were at a Jacob's Ladder event years ago and sharing how that shaped them. These are the precious moments that remind us of Jacob's impact on the world around him.

Jacob's Ladder didn't stop here, and in some respects, created it's legacy (already in full swing); Project Giveback. Project Giveback has run with what Jacob's Ladder started, taking that desire to give back, to be philanthropic, and develop our future community leaders.

Both Ellen and I are so grateful for all that you have done to create this opportunity for Jacob to impact the world around him in such a meaningful way.

Thank you for your continued support.

Jeff Schwartz (and Ellen)

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Best Version Media



Spreading the Word on Genetic Screening

During the year, along with our advertising highlighting the need for genetic screening, Ellen Schwartz continued to speak to a number of groups about life with Jacob, the lessons learned and how important it is to be screened.

On October 23rd, Jacob's Ladder once again attended the Shabbat Project Challah Bake along with our partners the Mount Sinai Genetics Department and The National Council of Jewish Women (Toronto). This amazing event was a great opportunity to reach over 900 (yes, over 900) women and girls who attended to learn the art of making the perfect challah. This exciting and just plain fun event was an ideal opportunity for Jacob's Ladder to spread the word on the importance of genetic screening. With information handouts, copies of Ellen's first book "Lessons from Jacob" and genetic counsellors on hand, attendees had the opportunity to head home with their challah and a lot of very important information.

REMEMBER - If you are hoping to have children in the future, please see your family doctor to make arrangements for this important step in family planning.

