



WHAT'S INSIDE

PAGE 2

- The MukiBaum Foundation
- Take the Jake Challenge
- Another Proud Moment
- Getting Married
- ECHOage

PAGE 3

- Norman Saunders Jacob's Ladder International Research Prize for 2017
- Jacob's Ladder and Sick Kids
- Jacob Trossman Update

BACK PAGE

- To our friends at Jacob's Ladder
- A Note From The Office
- The Annual Challah Bake 2017
- Awareness

Board of Directors

Robert Eisenberg
Vered Feldman
Peter Levy
Laurel Linetsky-Fleisher
Jeremy Friedman
Alan Schwartz
Ellen Schwartz
Jeff Schwartz
Ben Virgilio

Board Advisors

Bert Stitt
Harvey Taraday

Executive Director

Nora Glass

Newsletter Contributors

Jeff & Ellen Schwartz
Marcy White
Nora Glass
Dr. Monica Justice
Esther Leung Tou

Jacob's Ladder

505 Consumers Road,
Suite 400
Toronto M2J 4V8
Tel: 416-485-0078
Fax: 1-800-611-2449
info@jacobs ladder.ca
www.jacobs ladder.ca

I Rise Above

Music fuels Jake's soul. Ever since he was a young boy, we have invited musicians into our home to sing for Jake. To honour Jake's twentieth birthday, we brought together many of Jake's talented friends to write a song to commemorate this massive milestone. A group of six collaborated over six Sunday afternoons. The song is written from Jake's point of view. If Jake could share his thoughts, what would he say? Once we felt we had the perfect song, we brought in the entire group. Eighteen talented people ranging from ages twelve to sixty-six participated. Most of the performers were teenagers. Teenagers choosing to spend their Sundays singing with Jake. Is there anything more beautiful than that? Of course Jacob helped direct the music and the lyrics by his responses.

Funds from this song go directly to Jacob's Ladder's initiative to fund day programs for young adults with severe and complex special needs, and is available for purchase through iTunes.

Special thanks to Jack Lenz, Harrison Lenz, Stacy Zosky, Jennifer Zosky, Seth Zosky Shiller, Zachary Levy, Michelle Newman, Jonelle Grossman, Halle Burnett, Samarra Prenick, Aja Neinstein, Alex Gouchtchina, Mike Freedman, Mitch Belman, Don Denaburg, Tyler Simmons, Cole Perelmuter, Ethan Young, Ben Schwartz and Bevy Schwartz.

Here are the lyrics to "I Rise Above"

Come in from the cold on a Sunday
I've been waiting for you
Pick up your guitar and play me a song
Let the music lift our souls
I love the sound of your voice
And your fingers on strings
This moment with you is more than enough
The melody is all I need

Chorus

*You may not hear me, I am a message of love
When you are near me, it's you I'm thinking of
No need to fix me, I am my own perfect soul
There's a reason, I am here, I am love
I rise above*

Come into the water on a summer's day
Let me lay there in your arms
On the waves I'm floating away
This moment is all I need

Chorus

*You may not hear me, I am a message of love
When you are near me, it's you I'm thinking of
No need to fix me, I am my own perfect soul
There's a reason, I am here, I am love
I rise above*

One day I will show you I can fly
I will leave my wheelchair behind
One day I'll leave this earthly ground
This body no longer I'll be bound

Chorus

*You may not hear me, I am a message of love
When you are near me, it's you I'm thinking of
No need to fix me, I am my own perfect soul
There's a reason, I am here, I am love
I rise above*



A Note Of Thanks From The MukiBaum Foundation



Thanks to the incredibly generous donation Jacob's Ladder gave to the MukiBaum Accessibility Centre, the Centre is able to continue its mission in providing the key to accessing ability to all of the families it serves. This continued support

from Jacob's Ladder enables us to annually renew granting stipends to families that struggle to cover the tuition fee of their sons/daughters who are participants in the Adult Day Program. Furthermore, many new applicants are unable to register for the program due to lack of funding, for which there is a long wait for approval. This year the MukiBaum Accessibility Centre made a decision to offer a small stipend to families waiting for funding to cover one-day a week participation at the Adult Day Program as transition to the time when their funding will be established. It is through the generosity and amazing commitment of Jacob's Ladder that the MukiBaum Accessibility Centre has the means to offer this stipend and also provide families already in the program with funding to bridge a couple of months each year when their annual funding is not sufficient. The MukiBaum Accessibility Centre graciously and humbly thanks Jacob's Ladder for once again helping them provide the key to accessing ability. It is in this way that Jacob's Ladder, together with MukiBaum, may continue to improve the lives of individuals and families with developmental disabilities across the GTA.

Take the Jake Challenge

Against all odds, Jacob is able to live life to the fullest.

For 20 miraculous years, he has followed these 3 simple rules:

**He appreciates everything and everyone.
He lives in the moment.
He's so positive.**

Here's how the bracelet works:



Turn the shiny bead towards your heart every time you find yourself following Jake's rules. If you slip, turn the bead away from your heart. Seem simple?

Give it a try and take the challenge!
I know when I follow Jake's lead my day is a whole lot brighter.

Love, Ellen (JACOB'S MOM)

Look out for our new design coming soon

The Jake Challenge is a special project of

Jacob's Ladder
www.jacobsladder.ca

JACOB'S LADDER IS PROUD TO PRESENT

WATER SERIES

By Toronto photographer Jodi Chapnik

Featuring Jacob's sister, Beverly Schwartz, swimmer at heart



Night Swimming with Beverly



Within Reach



Glide

Feel the magic of water in these Limited Edition Prints
100% of sales donated to Jacob's Ladder

For enquiries
EMAIL: jodi@email.ca
WEBSITE: jodi.photo
INSTA: jodi.photo

Another Proud Moment

Jacob's Ladder joins The National Council of Jewish Women of Canada in saying congratulations and mazel tov to Dr. Cheryl Rockman-Greenberg who will be inducted in April 2018 into the Canadian Medical Hall of Fame. Cheryl is a member of NCJWC and is a geneticist, paediatrician and the person who created the new NCJWC genetics brochure, published this year together with financial assistance from Jacob's Ladder, Dysautonomia Foundation and Fanconi Canada. Cheryl was the Medical Director of the Winnipeg Regional Health Authority's Child Health program and Head of the Department of Pediatrics University of Manitoba from 2004-2014 and is recognized for her extensive research into genetic diseases, which gives hope and a future to many.



Meaningful Parties for All Occasions



ECHOAGE

**A Better Way
To Celebrate**



LEARN MORE

Through our partnership with ECHOage and their "All Occasions" parties, everyone can make a difference raising money and awareness on their special day. It's easy, it's fun and it's meaningful. Find out more at ECHOage.com



The Jacob's Ladder Norman Saunders International Research Prize for 2017

This year The Jacob's Ladder Norman Saunders International Research Prize, named in memory of Jacob's beloved doctor, recognizes the outstanding work of Mustafa Sahin M.D., Ph.D. Dr. Sahin is

a specialist in the field of childhood neurological diseases and currently holds the position of Director, Translational Neuroscience Center and Professor of Neurology, Harvard Medical School.

Dr. Sahin received his MD and PhD in neurobiology at the Yale University School of Medicine. He completed his internship at Children's Hospital of Philadelphia and residencies at both Children's Hospital of Philadelphia and Boston Children's Hospital. He has received numerous awards, including a Mentored Clinical Scientist Development Award, a William Randolph Hearst Fund Award, a Spinal Muscular Atrophy Foundation Young Investigator Award, the 2005 Young Investigator Award from the Child Neurology Society and a 2009 John Merck Scholar Award.

Dr. Sahin's research investigates the normal cellular functions of signaling pathways implicated in neurological disease, with an emphasis on axon growth and guidance. Further focus is on the proteins affected in tuberous sclerosis complex (TSC) and spinal muscular atrophy (SMA) – two neurological disorders whose genetic basis is well understood but whose cell biology remains unknown. By understanding and developing new mouse models, Dr. Sahin has advanced treatments for TSC that have changed clinical practices.

As a clinical neurologist Dr. Sahin has an active practice treating patients with neurological disease. His overall goal is "to bring new treatments to childhood neurological diseases and improve the lives of children and families affected by these conditions."

We look forward to welcoming him in Toronto to receive his award on January 17- 18, 2018. He will speak to Paediatrics Grand Rounds at the Hospital for Sick Children on Wednesday, followed by the award reception, and speak at Genetics Rounds on Thursday.

Jacob's Ladder and Sick Kids



Jacob's Ladder has had a long relationship with The Hospital for Sick Children, beginning 20 years ago when Jacob was born. Throughout the time since, as the Hospital has supported Jacob, so has the Foundation supported the Hospital through enrichment and research programs. We are happy to announce that once again this

year we are funding a research project that may have implications for Canavan disease and other related disorders.

Dr. Gabrielle Boulianne, Senior Scientist in developmental and stem cell biology at the Sick Kids Research Institute presented two outstanding existing projects that would definitely benefit from additional funding. In our view, either project would be an excellent choice, and as we are so impressed with Dr. Boulianne's research experience, commitment and vision, the Jacob's Ladder Board of Directors has allowed her to choose where to apply our funding for this one year project. We look forward to working with Sick Kids, Dr. Boulianne and her team.



Jacob Trossman Update

Following a couple of rough years of illness and recuperation, Jacob was back on track and able to start the school year with his friends last September. In June, he graduated from Dublin Heights Public School and received the Principal's Award for Student Leadership. September 2017 brought a new change: Jacob is now a grade 9 student at Lawrence Park Collegiate Institute and shares a class with Ben Schwartz!

Thank you for your continued support and please keep checking Jake's blog at curepmd.com/blog



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

To our friends at Jacob's Ladder from Park Lane Public School

Thank you from the bottom of our hearts for your generous donation to the Music Programs at our school. These funds will be used to support Musical Performance Events such as the Bell Choir, the Toronto Symphony Orchestra, Black History Month performances and also the purchase of essential sound and musical equipment and instruments to support our music. Music is a universal language for all our students. Park Lane Public School is a congregated school for students with developmental disabilities. Our students range from ages 4-21, coming from all over Toronto - all of them with their special unique strengths and complex needs. The students thrive as they are in an environment that promotes learning and independence. However, at age 21, the students are no longer eligible to attend public school and their education is halted. There are very few options and certainly none that provide a comparable learning environment. Different challenges arise for our parents, and many do not end up in appropriate engaging programs because cost is too high, there is no room or funding to support complex medical needs, and the transportation to and from the program is an issue.

As a community from congregated schools, we are committed to continuing the dialogue to address the gap in services for adults with special needs Post-21. A group of parents formed a steering committee to look at building Post-21 programming. The vision of the committee is to brainstorm solutions to meet the gaps in service currently experienced by our community and to engage the wider community in this discussion. We are urging everyone to get involved in this important endeavour and support the programming Post-21 for Young Adults with disabilities.

A Note from the Office...

Oh, those kids.

When Jacob's Ladder started some 19 years ago a child was at the centre of it. And still is, thankfully. But really, outside of some developmental issues, Jacob is now an adult. Time moves on. With that passage of time, you never really know the kind of impact someone has on another, on a group, or even a community until something spontaneous occurs. Sure, we have seen the upshot of the events, the funds raised, the results of the research and the life changing decisions from the genetic screening. However, it's the generation of Jacob, that is only now, entering centre stage.

If you ask Ellen, that was all part of her master plan once she started taking over the fundraising events; But wow! Has it ever worked. Now that sounds as though all of what has been done over the last 10+ years has been scripted and choreographed, not so. It began with a change in direction, a new idea we hoped would take hold, nothing more than just a concept. Jacob's Ladder certainly didn't do this in a vacuum, it's been going on all around us and for some time now. Somehow it's different, it's more relevant because is it our children, friends of our children, or better yet, someone who attended a Jacob's Ladder event when they were 5, and now they are 17.

Philanthropy, giving back to community, paying it forward,

getting involved are not new ideologies, they have been handed down for generations. I saw it with my great grandfather, my grandparents, and with the greatest impression, my parents and in-laws. I can't remember a time growing up where our dining room table wasn't covered with letters or pamphlets and envelopes that my mother was stuffing for one charity or another. However, when you see it growing right before your eyes, with the backdrop of all the horrible things we are presented with multiple times a day, it takes on a new and special meaning.

Quite frankly, it's humbling and inspiring at the same time. Maybe those two adjectives go hand in hand; first we are humbled then we are inspired. I don't know, but the effect is empowering. Over the last number of years with the ease of access to so much news, we can become jaded in our opinions and actions. It is disheartening and it takes its toll on everyone. All of these atrocities are real and shouldn't be ignored, however with all the humaneness happening out there too, I choose to be enveloped by that. Jacob's Ladder has helped to make that happen thanks to you (and your children).

Check out what some of these kids are doing at #nspireband and #project_give_back, you will be blown away.

Thank you for your continued support.

Jeff Schwartz (and Ellen)

The Annual Challah Bake 2017

We were there! On October 26th Jacob's Ladder joined several members of the Genetics Department of Mount Sinai Hospital and partners at National Council of Jewish Women of Toronto to host a genetics awareness booth at the Annual Toronto Challah Bake, organized as part of The Shabbat Project. Attended by a large crowd of eager bakers, young and young at heart, the crowd was able to obtain screening requisitions, brochures and packages including information on services available for both the Ashkenazi and Sephardic populations, expanded self-pay options, cancer treatment options and general brochures on IVF, family planning and prenatal testing standardly offered to all people in Ontario.

This fun and upbeat community event was a great success and also a great opportunity to offer information to this happy group of new Challah mavens.

Awareness: Genetic Screening, Insurance and You

The passing of Bill S-201, or the Genetic Non-Discrimination Act, in March of 2017 ensured that no person can be required to undergo genetic testing nor disclose previous results of any testing that they have had. Many people have balked at being tested or having their children tested out of fear of raising problems later in life, mainly around the issues of being able to obtain insurance or employment after revealing their results. Genetic testing is carried out for many reasons, including to diagnose particular diseases and symptoms to assist in providing best treatment or to determine inherited genetic diseases so carriers can make informed decisions on how to move forward with the assistance of genetic counselling. For further information please refer to Government of Canada Bill S-201 or LEGISinfo-Senate Public Bill S-201 (42-1).