Shemini: The Eighth

THE WHY'S, HOW'S AND VALUE OF PARTICIPATING IN AUTISM RESEARCH

What I am going to be talking about today…

▶ Welcome and Introductions

▶ The Title: Shemini (The Eighth)

▶ My Story and Lessons Learned

▶ Parents' Roles in Autism Research

▶ Examples of Parent and Patient Input into Autism Research

▶ A Proposed Model for Parent Involvement

▶ Personal Insights and Reflections: Just do it!

▶ A Personal Philosophy

TedxYorkU Salon: **#TEDxYorkUSpectrum** An Example

- [TedX York University](#)

- [Finding Your WAZE: A Parent Perspective](#)

ADVOCACY   TEDXYORKUSPECTRUM
Marg Spoelstra
COMMUNITY ADVOCATE

ADVOCACY   TEDXYORKUSPECTRUM
Doug McCreary
PARENT

ADVOCACY   TEDXYORKUSPECTRUM
Cynthia Carroll
COMMUNITY ADVOCATE

ADVOCACY   TEDXYORKUSPECTRUM
Esther Rhee
COMMUNITY ADVOCATE

ADVOCACY   TEDXYORKUSPECTRUM
Connie Putterman
PARENT

COMEDY   TEDXYORKUSPECTRUM
Michael McCreary
SELF-ADVOCATE

SOCIAL SCIENCE   TEDXYORKUSPECTRUM
Aryeh Gitterman
RESEARCHER

HEALTHCARE   TEDXYORKUSPECTRUM
Yona Lunsky
RESEARCHER

SOCIAL SCIENCE   TEDXYORKUSPECTRUM
David Nicholas
RESEARCHER

LIFE   TEDXYORKUSPECTRUM
Daniel Share-Strom
SELF-ADVOCATE

Holland Bloorview Research Institute Symposium: Ely's Thoughts about Participation in Research

- [Holland Bloorview Research Symposium](#)

A Model for Parent Involvement in Research

- The Concept
- The Inspiration: Turning Lessons Learned into Action
- The Goals
- Proposal for a Pilot Study

The Concept:

Including parents in the creative research process, is it possible, is it realistic?

My concept around this for autism research is to create a framework so that research is inspired by parent insights without unduly restricting the researchers. I also hope that it will lead to a framework that helps various disciplines from various parts of the world work together.

The Inspiration: Turning Lessons into Action

- Parents know their child best
- There is value in multiple perspectives and experiences
- There is exponential value in creating small successes
- Need for more "control" families in research
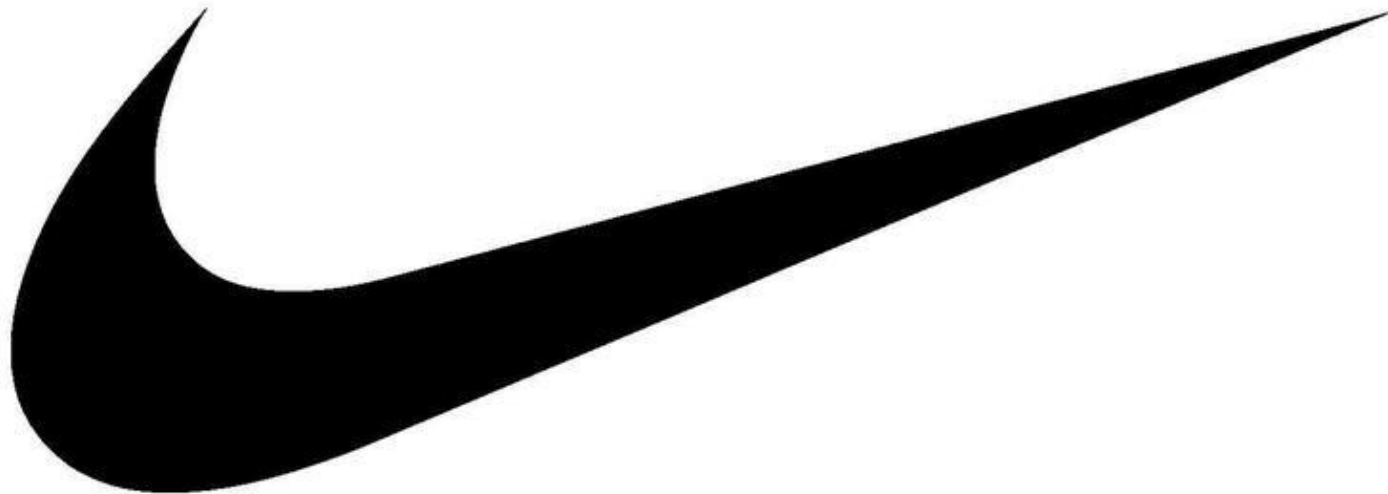- Models of inclusion show benefits of multiple perspectives

The Goals

- Run a pilot study to look specifically at collaborations between scientists and parents on autism research projects. This requires a person to "liaise" between parent and scientist and to manage the interaction

- Take lessons learned from "pilot study" to benefit the design and utility of all future research projects

- Create a model for ensuring positive parent influence and inclusivity

- Ensuring that researcher autonomy is not compromised

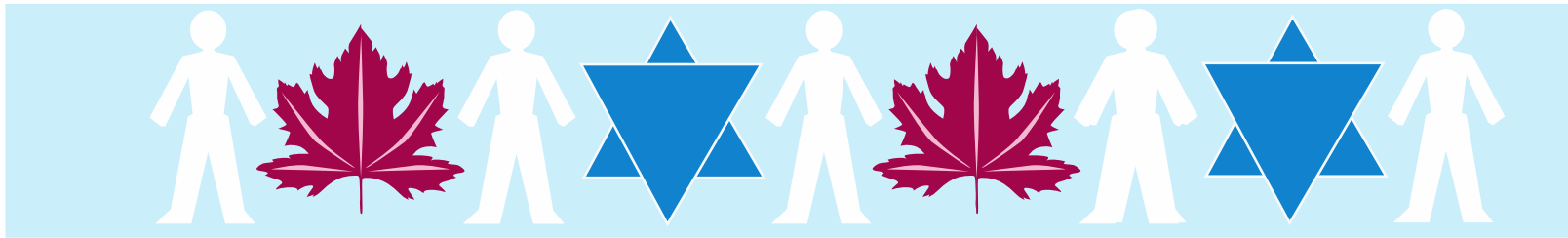# The Proposal for the "Pilot Study"

- Part A: Study a sizable sample of previously funded autism research projects to identify the nature and extent of parent input and/or inspiration for the research project. The review would attempt to assess how the level of parent involvement impacted on setting the goals for the research, the design of the research, and the conclusions reached.

- Part B: The second phase would be to analyze the results, and then survey a parent group and a researcher group with a view to making recommendations for improving autism research by including parent perspectives at every step.

Just Do It

My Personal Philosophy

▶ "I would like to see research inspired by parents. It's parents that are closest to their child and its the parent's job to help the child grow and develop. In this capacity, the parent becomes an interpreter and an "enabler", interpreting the actions of their child and enabling others to see the value of that child and begin a movement toward change. I also believe that it is within this process that a child is to able to develop into a true leader. I believe that one day our children will show us all how to lead and we will have captured the essence of who we all are as individuals"

CANADA ISRAEL Autism Research Initiative

Connie Putterman, Founder / Co-ordinator   cputterman@rogers.com   www.autismcanada-israel.com

E-Mail: cputterman@rogers.com

Web site: autismcanada-israel.com

Facebook: @autismcanadaisrael

YouTube: #TEDxYorkUSpectrum

Blog: cputterman.tumblr.com

Twitter: @cbputterman

Thank you!