Speech to Hebrew University in Jerusalem- Parent Research Day June 25, 2017

By: Connie Putterman, Toronto

***Slide: Shemini, (Eighth)***

June 25, 2017

***Slide: What I am going to talk about today…***

1. **Welcome and Introductions**
2. Parents’ Roles in Autism Research, An Introduction
3. **Title of my Talk: Shemini (the Eighth)**
4. **My Story**
5. Personal Connection and Benefits
6. **Lessons Learned**
7. **Parent Role in Autism Research**
8. The Importance of parent Involvement in Autism Research
9. Defining Research in the context of Parent/Research Partnerships in Autism
10. **Examples of the “New Directions” in Autism Research**
11. **A Proposed Model for parent involvement**
12. **Insights and Reflections, “Just Do it”**
13. Why it matters: Each of you has an individual story to tell
14. A positive outlook may be good for your health
15. Back to Shemini
16. **A personal philosophy**

**Welcome and Introductions:**

Good afternoon. My name is Connie Putterman and I am very happy to be here with you today. For me, I am especially proud today to see you all here. I am proud to say that it was only a few years ago in Toronto that Dr. Michal Begin and I talked about our “shared vision” for an Autism Centre at Hebrew University, and a shared vision in general for helping to advance the field of autism in Israel. In 2014, we held the first ever Canada/Israel Autism Research Conference here at Hebrew U and since that time, so much has happened! From the kernel of an idea, to the commitment of many wonderful people including Dr. Judah Koller and Dr. Cory Shulman, here we are today making that vision a reality.

The goal of my talk today, is to convey to you the importance of the role of parents in autism research. In the first part, I will talk about our family’s experience and my involvement in autism research as a parent of a child diagnosed on the autism spectrum. In the second part, I will speak more broadly about parents’ roles in autism research and propose a model for how it might work including examples.

It has been over 17 years that our family, and most particularly me, has been participating in the autism research community. I have put a lot of personal time and energy into this role, and have been speaking about it both in Canada and in Israel. Some of you may have heard me before, or seen my TedTalk. It’s a personal story, a “lived experience” that keeps evolving. Over the years, my role and involvement has changed and deepened. It’s changed both by my own interest and the will of the autism research community. The time is **NOW** for parents to come forward and get involved. It will make a difference.

Now, before I begin, I wanted to explain why I chose this title. Shemini

**Shemini is the 26th weekly Torah portion or parsha**. It means “the eighth”. It includes the very difficult story of Aaron’s sons, one that is hard to understand because of the events that happen in it. So why is this story significant to my talk? In past talks, I have referenced Disney movies, or Leonard Cohen songs. But only in a Hebrew speaking crowd can I reference Shemini. For one, Shemini was the Torah portion for my son’s bar mitzvah five years ago. It has special significance to me for that reason alone and I even chanted the 4th Aliyah. But more recently, I heard a scholar interpret the parsha in a way that resonated with me, and helped make sense of the story for me. He talked about the eighthday as meaning “the day after”. The day AFTER is the day of assuming new roles, getting on with new responsibilities, or starting fresh. For me, this has been a life lesson, and one that reminds me of that most formidable question “How do we begin the day after?” Figuring this out, is by far the hardest step.

**Our Story**

Our story begins almost 18 years ago, when our son Ely was only two months old. I responded to an advertisement that was posted in our pediatrician’s office in Toronto. It was a request for “alert, two month old control babies” for an autism research study at the Autism Research Unit at Sick Children’s Hospital in Toronto. I responded for a number of reasons, perhaps because he was a very fussy, “alert” baby. But mostly, I responded out of curiosity. I knew nothing about autism since my background was in business management, but I appreciated the value of research. So, I took my healthy baby to “Sick Kids” (as it is called) where we participated in an eye tracking study as part of a control group. There, with Ely positioned in my lap, he stared at changing multiple digital images on a wall as his eye movements were tracked. It was our first time participating in an autism research study. After that first session, we went back for repeat visits at four months and six months of age. And then, I didn’t think about it again for or a while. Ely was just a “control” baby.

When he was twelve months of age, my in-laws, noticed Ely wasn’t looking at them. Without hesitation, they expressed concerns about autism and we took their concerns seriously. So I returned to the autism research centre at Sick Kids and after a few months of persisting very actively, we received a formal diagnosis of autism when Ely was just over seventeen months of age. At the time, he was among the youngest diagnosed on the autism spectrum at Sick Kids. And on that early September day, the developmental pediatrician handed us a questionnaire to complete. She was a leading autism researcher in Canada and she wanted to learn about our early experiences and what had prompted us to bring Ely in for an assessment. So, we completed the questionnaire. It was now our second time participating in an autism research study, but this time, not as a “control”. It was an entirely different experience! And, as you can imagine, one with overwhelming sense of uncertainty and fear. I won’t ever forget these moments and how we felt.

Soon after the diagnosis, I had the opportunity to talk to another well-known autism researcher who was able to give me hope, that at this early age and stage, and with the appropriate intervention, our child had a significant chance to manage in the world. But what does that mean the **right intervention**? What did I do with the promise of hope? It was a daunting task and an overwhelming challenge to find the interventions that met the specific needs of our child. It certainly wasn’t easy.

We had to find a path of intervention with little mentorship available or known to us at the time. There was no one specific person or professional mentor to guide us through the emotional roller coaster of a diagnosis nor to help us with an intervention strategy. Prognosis was also an elusive notion and uncertain at best. We had to figure things out for ourselves. The early diagnosis was a starting point however there certainly was no road map for moving forward. The answer for me lied in - “doing things”- and not fretting. I know that I learn best by doing. My path for understanding autism and navigating interventions, the service sector and health system was through participation in autism research studies. And since that time, we have participated in many studies as a family and individually.

But it was so much more than that!

Research participation enabled me to have a voice in the autism science community. With the full support of my husband, I quit my job to devote my time to the management of Ely’s early intervention program and to pursue my research involvement. As I continued to participate in autism research studies and join autism research committees as a parent representative, I gained the respect of the research community and viewed myself as contributor to the research dialogue. During the course of the next few years, I took the opportunity to learn from the best minds in autism. I attended conferences and meetings and formed personal relationships with a variety of experts in the science of autism. As a result, I had direct access to relevant information that you can’t get from books or articles. Those I met also had direct access to me and I didn’t hesitate to contribute. My personal choices were more informed around treatment and care of our son. Most importantly, I made a shift in my own identity as a parent of a child with an autism diagnosis. I no longer felt as if I was in a vulnerable or helpless position. I could advance a cause that is very important to me, in a way that was productive and positive.

Since that time, I have continued to contribute in many different ways to the autism research and neurodevelopmental community back at home in Canada and here in Israel. In Canada, I advocate at scientific forums and speak publically about parent involvement in autism research for a number of children’s brain health research networks. I continue to advise these organizations on the parent perspective and impact, co-chair their advisory committees and even have participated as a journal reviewer for a children’s health research publication. Most recently I co-authored a paper on autism, inclusion and bar mitzvah. In Israel, I liaise with many different autism research groups around the country to promote collaborations and have travelled extensively to learn about autism and autism research in Israel from north to south.

**Lessons Learned**

I have learned some very valuable lessons over the past few years.

**Number one**: I learned that parents understand their children better than anyone. This knowledge needs to be channeled where it has the most impact. Parents’ knowledge informs research.

**Number two**: I gained confidence and knowledge through research participation that allowed me to appreciate the multiple roles and type of relationship I could develop with my child‒as a model, coach, teacher and therapist. I learned to accept that I had to be more than just a –“mom”- which, at first, I struggled with. Over time, I became well versed in the appropriate vocabulary for discussion about autism. Most particularly, I became less anxious about it too. I needed to talk about autism with my son, and it became easier.

**Number three**: The appreciation gained from the many perspectives including my husband’s, family and friends was invaluable. I learned to listen to their advice, I neither could nor should manage this alone.

**Number four**: Research doesn’t solve everything instantly nor does research answer all of the questions. I discovered many myths about research and I learned to stop fearing the unknown. I discovered opportunities and new ideas that I could explore with people that were interested in listening.

**Number five**: Everyone has something unique to offer, and it’s important to identify our strengths and work with them. For me, it was not productive to dwell on the things that had passed, or to ruminate about why this had happened to me. I learned that taking action is empowering.

 **Parent Role in Autism Research**

The role of parents in autism research is important primarily because of the balance of perspective it brings to autism research and the knowledge and empowerment that it brings to parents. Many scientists in the autism world don’t know people with autism. Many parents with children on the autism spectrum don’t know or understand research and the impact they can have. I would argue that currently the direction of research in autism is not sufficiently parent influenced and there needs to be a balance between the pure scientific and clinical research and the parent perspective so that everyone benefits.

I would also argue that how you perceive and define research will impact how you participate. If you view research as something that is done in a lab, or with mice far removed from daily life, it will seem impossible to penetrate and not relevant to you. If you think of research as something that takes years to do with little impact on your child, you will never take that first step. If you believe that research is for scientists only, then your story won’t ever be heard. But if you consider yourself **“relevant”** to the research and discovery process, the likelihood of you taking that first step will increase greatly.

In a research context, at many universities in Canada, the parent and patient influence and perspectives are helping to re-shape the narrative of autism research. Directors of autism research centres are making sure they include multiple perspectives. This is shaping how new research goals and projects are being designed and implemented. For example, consider how Toronto’s York University used a small part of a large grant for autism research to fund a **Ted Talk or TEDx Forum** on Autism Research in Canada. It was organized by the Autism Centre at York University to promote education in autism research. The event was held in a live theatre with a live audience over the course of an afternoon.

***Slide TedxYorkU Salon with web page link***: <http://www.tedxyorkusalon.org/?page_id=262>

If you look carefully at the variety of presenters, they are community advocates, parents, self-advocates, and researchers who all have very different perspectives. Some talk about personal stories, with humor and wit while others give specific details of issues facing their communities. After the event, the young adults with autism and the parents received the most “hits” on their YouTube channels. There is clearly a desire to hear from the parents and families.

Another example was an event that took at Toronto’s **Holland Bloorview Children’s Research Institute.** The theme of the symposium focused on the impact of families engaged in research beyond the role of participant, and demonstrated the real life value of patient engaged research. The following is a segment from the symposium of my son Ely answering questions about his involvement in autism research studies, and here in particular, he talks about his views of “Google Glasses” to help with social ques.

*Watch the clip…*

The future direction of autism research must include parent involvement. I proposed one model for parent involvement to a Canadian Research Institute and how or what it could look like. The following is part of the model.

 ***Link to slide presentation****:*

***Slide: A Model for Parent Involvement in Research***

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

***Slide: 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.

***Slide: The Inspiration***

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

***Slide: 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 the 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

***Slide: 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.

**Insights and Reflections: Just do it!**

***Slide of Nike Swoosh***

It matters that you participate. Each of you has an individual story to tell, but it is the sum of all of the stories that will balance the perspective in research. It is the collection of this information (as data) that will also form the basis for evidence that can influence and change the future direction, the future funding and the future influence on public policy for autism research. It will also influence policy direction and public awareness and the future needs of those affected by autism. That’s a lot of influence.

I recently read an article in the NYTimes that a positive outlook may be good for your health. That it actually improves health and extends life. I would also suggest that a positive outlook also influences those around you including your family and children, and others such as researchers, and clinicians. I hope that by sharing your insights, you too can benefit from the positive effect of doing so.

**Conclusion**

As I said at the beginning, Shemini means to me “the day after”, or starting fresh. That is what I am asking you to think about…

*I also want to share with you my personal philosophy…*

***Slide of Quote:* A Personal Philosophy**

“I would like to see research inspired by parents.  It’s parents that are closest to their child and it’s 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” Thank you.