



## In this issue:

- **Sarah's Story**  
Learn how a clinical trial at Duke University impacted a young girl with Autism



*We need to stop throwing out these stem cells as medical waste; they are pure gold. By using a private bank, we had our own stem cells for our own use. NECBB's [staff] was knowledgeable and easy to work with, no stress at all. I read on various social media groups that parents discovered that their stem cell samples were contaminated after they applied for a trial. Other families couldn't get their medical reports or specimens released from their cord blood bank. These other banks put some children's acceptance in the trial at risk.*

**-Anna, Sarah's mom**



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**There are stem cells in your child's teeth!**

**Why consider storing them?**

*Like cord tissue, teeth have Mesenchymal stem cells (MSCs), which can form many types of tissues.*

*learn more at [ndpl.net](http://ndpl.net)*



**A 2<sup>nd</sup> chance**

Families who did not have the opportunity to store the MSCs from their children's cord tissue now have a second chance to preserve MSCs from **their teeth!**

## SARAH'S STORY

# Treating Autism with Stem Cells

Duke University Clinical Trial



In 2010, Anna and her husband decided to bank their son, Ryan's, cord blood with New England Cord Blood Bank, Inc. (NECBB). Two years later, when their daughter, Sarah, was born, they opted to do the same.

When Sarah was diagnosed with Autism, Anna thought about the possibility of using cord blood stem cells for treatment, and began a quest to research medical advancements in stem cell therapies that could potentially benefit her daughter's condition.

Anna joined Facebook Groups and scoured the internet looking for potential treatments for Sarah. After a year of researching options, Anna discovered a clinical trial run by Duke University. If accepted, Sarah could use her own stem cells to participate in the study. In June 2016, she was accepted into the trial.

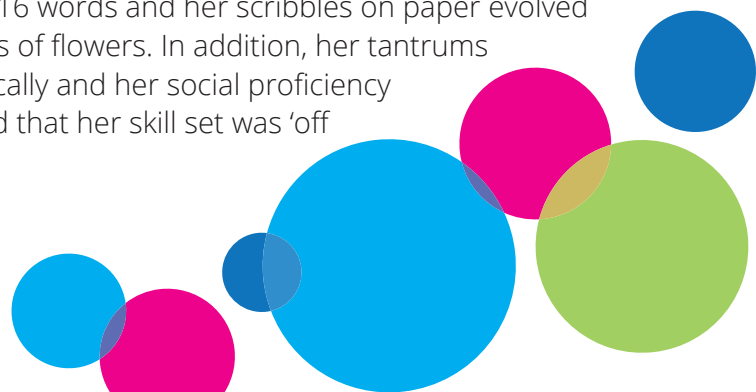
NECBB coordinated with the family and Duke University Hospital to oversee the logistics of transporting and delivering the cryopreserved stem cells for Sarah's treatment. With high hopes, mother and daughter journeyed to Durham, North Carolina for the trial therapy.

Sarah's first treatment was completed in February 2017. The family did not observe any changes in Sarah at that time. Her speech and language skills remained below grade level, her drawings were simple lines on paper and she remained socially awkward.

Since the Duke University Hospital Study does not disclose clinical trial treatment information (placebo or stem cells), Anna speculates that the first treatment was, perhaps, a placebo. She does not know for sure.

After Sarah's next session, dramatic improvements were noted. In less than a year, Sarah's language improved from two and three word sentences to 16 words and her scribbles on paper evolved into detailed images of flowers. In addition, her tantrums decreased dramatically and her social proficiency evaluation indicated that her skill set was 'off the charts.'

*Continued...*



# Sarah's Story

CONTINUED

Since the clinical trial at Duke University Hospital did not report the individual outcome to each participant, they only release a general report of the cumulative results, Sarah's success was evaluated independently. She is still on her Individual Education Plan (IEP) at pre-school, but her mother reports that everything is better. "It's not a cure and there are still challenges, but there are improvements across the board." Anna notes that there are still lots of hurdles and developmental delays, yet their daughter's progress has been exhilarating for the family.

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*Sarah's language improved from two and three word sentences to 16 words and her scribbles on paper evolved into detailed images of flowers.*

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But Sarah's story isn't done yet. Her brother, Ryan, is a partial (50%) HLA match and therefore his cord blood stem cells can be used to extend her treatment. Anna has registered Sarah for an allogeneic (using stem cells from a donor, in this case Ryan) transplant this month as part of Duke's Expanded Access Protocol.

Anna remains hopeful that there will be a mesenchymal stem cell (MSCs) clinical trial for autism in the near future. MSCs are "building block" cells that not only can self replicate, but can also differentiate into many different cell types. With that trait they could one day repair or replace a wide variety of tissues, such as bone, cartilage, neural cells, muscle cells, and so on. MSC's can be found in umbilical cord tissue and dental pulp. Anna said she wishes she had stored Sarah's umbilical cord tissue



when she preserved her cord blood. (NECBB offers the option of storing umbilical cord tissue, a source tissue of MSCs). Additionally, NECBB's affiliate company, National Dental Pulp Laboratory, Inc. (NDPL) processes and stores MSCs collected from dental pulp or extracted teeth.

Anna added, "I'm excited about the potential of treatment. I hope that soon the FDA will open the floodgates so people can have access to this therapy. It's safe, so let people benefit from it."

NECBB has shipped her sibling's specimen to Duke University for Sarah's additional treatment. Anna is hopeful that Sarah will show continued development in combating the symptoms of Autism. She said the results to date have been astonishing; Sarah continues to flourish as a 5-1/2 year old girl. She is thriving in school and enjoying life with her friends.

NOTES: The names have been changed to protect the anonymity of the participants. This reviews the results of a Clinical Trial; the FDA has not approved stem cell transplants as a treatment for Autism.

Contact Us  
**774-843-2965**