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“Your baby has Trisomy 13. It is a syndrome incompatible with life”.....

I will never forget hearing those words, that day back in October. It was the 26th to be exact. I remember feeling as though all of my blood was draining out of me. Coldness ran through my veins. I could not take another breath.

I felt as though I had just left my body. It was an altered state that I do not have the words to describe.

All of the hopes and the dreams that I had for my precious baby and I were gone.

I would never rock him to sleep. I would never nurse him. I would never see him smile, hear him laugh, or even cry. I wouldn't see him shudder as he tasted his very first food. I would never see him sit, crawl or walk. There would be no first day of school. There would be no graduations. I would never kiss a boo-boo. I would never meet his first girlfriend, see him get married, or hold his babies in my arms.

These are the things that I looked forward to doing with Bennett-Chadlen, from the moment I found out that the pregnancy test was positive.

I imagined that at this time, right now, that I would be working in my flower gardens with Bennett-Chadlen in his carriage next to me. He would be 3 months old tomorrow.

Trisomy 13 is not always incompatible with life. There are many survivors that do go on to have ***“a quality of life”***, and their families ***“have a quality of life”***. Sadly, many won't hear about these stories when the dreaded words of the diagnosis are delivered to their ears.

I have heard from many families of ***“living”*** Trisomy 13 children, of various ages; ranging from the single digits, into the double digits to the 40's. Yes, that is correct. We know of a woman that is now in her late forties. How many do we not know about?

These parents are proud to report that their children are happy, and thriving, despite the poor prognosis that was also delivered to them in the beginning. I have heard stories of potty training, learning to crawl, taking their first steps. I have heard about the various ways in which these children have been taught to communicate. They understand so much more than many medical professionals believe that they will. If taught how to communicate, these children are capable of showing us how much they know, what they are thinking, what they are feeling, and what they are wanting or needing.

I've seen photos of smiling faces in strollers, or while sitting on their siblings laps, and even on horseback. I've seen videos of children swimming and laughing, singing, and rolling over. The list goes on.

Many survivors attend school. Like other children born without a chromosomal abnormality, they have their favourite movies, television programs, and toys. They smile and laugh. They sing. **They learn!**

Most importantly they evoke such joy in the lives of their family members, and others that know them. They evoke compassion and love in so many of us, without us ever having met them.

How can anyone say that these children do not contribute to society, therefore what is the point?

Do not assume that there is endless suffering in the lives of these children and their families. Do not assume that they are such a burden that caring for them takes away a quality of life to those that they live with. Do not assume that their parents wish they could trade them for a healthier child.

I have not heard from a parent yet that wishes their child had not been born, regardless of the outcome.

No parents want to see their child sick. No parent wants to see his or her child in pain. No parent wants to force his or her child to live with sadness. Trisomy parents are no different.

I honestly feel that the medical professionals believe that they are doing what is in the best interest for all involved by suggesting to expecting parents to “allow nature to take its course”. I believe that they feel our children will live with such a poor quality of life, that it is not ethically or morally correct to force life upon them by treating them with the same medical intervention that would be given to a non-trisomy child, either at birth, or later in life.

I believe that due to the lack of current research and data available to the medical professionals, ie....obstetricians, midwives, perinatologists, neonatologists, pediatricians, geneticists, genetic counsellors, bioethicists...etc...there will always be this false idea that Trisomy children are incompatible with life, have failure to thrive, and that they are medically futile most of the time.

As long as this is the belief of the medical professionals involved with the diagnosis and deliverance of the prognosis, many parents are kept in the dark about the truth. Many parents are offered termination, and due to lack of accurate information, sadly many parents choose this, only to find out in the future that some of these babies do survive. When these parents go on to read the stories of the survivors, or the stories of parents like me that have chosen to give life to our children, pursue life-saving treatment, and be with

them until they leave this earth, they live with extreme sorrow and regret. Many times they wonder if they did the right thing. Many times there is anger with themselves, and the medical professionals. When the shock has worn off, and they realize what has happened, they have to live with those choices.

Parents need to be given accurate medical information that covers all options. It often is not the grief that is difficult to overcome, it is the guilt that comes with feeling that perhaps something more should have been done.

Physicians need to accept the parents right to choose life, and support that decision 100%. No one should ever have to fight for his or her children to be given medical treatment, if that is what the parent wants. It should be offered, and **NOT have to be pursued.**

Bennett-Chadlen's brothers are grateful to have met their baby brother. They thank God for him each night in their bedtime prayers. They say 'Goodnight' to Bennett-Chadlen, tell him they love him, and blow several "Angel Kisses" his way.

Our lives have been forever changed in a very positive way by his existence. He may not be here in a physical form, but he will always live on in our place of favourite memories.

My sons will grow up with compassion in their hearts for the vulnerable amongst us.

Most of all, they will be proud of their mom for allowing their innocent baby brother to come into this world, against all the adversity surrounding his prenatal journey.

Life is precious regardless of the package it comes in. Respect it. It is not ours to take away.

Sincerely,

Melissa Roy—Proud mom of Bennett-Chadlen Roy, who blessed us on Earth for 8 glorious days and 9 months before that.

Forever in our hearts, forever in my soul.

Born at 40 weeks gestation on March 29, 2007.

Grew his wings on Good Friday, April 6, 2007.

BENNETT-CHADLEN ROY



"NIMKEE" "Little Thunder" March 29-April 6/07

