

## Blog for October 26, 2009 – stem cells are 5 months old today



Dear Dylan,

What an amazing journey you have taken us on. Not just us, but all the incredible people who have joined us in helping you to one day have a better future. Today it has been 5 months since you received a re-infusion of your own cord blood stem cells at Duke University. By now you know that when you were born, we banked your cord blood. No reason, really – mostly because we could at that time, and it was our thought that this was the greatest form of 'life insurance' we could buy you – the opportunity to have your own genetically matched stem cells stored for you in case you would ever need them. At the time, the thought crossed our minds that you may never need them, but to us, it was worth the price just for you to have them available to you one day.

Some day in the future, as you are reading these blogs, you will probably already know that you were one of the very fortunate children in the United States to be selected for a study at Duke University where children with Cerebral Palsy get to have a re-infusion of their own cord blood stem cells. So, even though we didn't think *you* may ever need those cells, the time did come, just 5 months ago, where that decision and those cells may be life changing for you.

I know that when you get older there will be a lot of blog posts to read, so every month on your new cells anniversary (we call this your new birth date), I am trying to post an update like this to you, so you will have a consolidated update by month. This is a long one, as much has happened in the last few months.

Although our journey with you has been about much more than this year, this blog narrows it down to this year alone, -- and I have to say, it has been nothing short of amazing. You are quite a little charmer and a great trooper. Your daddy is teaching you to say "abs of steel", as he does another round of sit-ups with you each day, but what we really need to teach you is to say "will of steel". You have the greatest spirit, and I believe you know that everything we are doing for you, is so that you will have a better (and hopefully easier) life.

Before your re-infusion, we began to search for a place in Oregon where you could have Hyperbaric Oxygen treatments after your stem cells settled in. For over a week, I called all over Oregon and could not find a chamber where you could be treated. Well, that all changed when I typed "Hyperbaric Oxygen +Bend" into Google and up popped Bend Memorial Clinic. Your father and I smiled when I told him that Bend had HBO chambers, as we both love the Bend area. I thought, maybe, just maybe, that will be the place that will take you. When I called, the receptionist asked me to fax our medical records and a fax explaining our situation. There was a long pause on my end, and after I explained that



*Dylan at Duke after his re-infusion – May 26, 2009*  
*One of less than 50 children in Duke's Study*

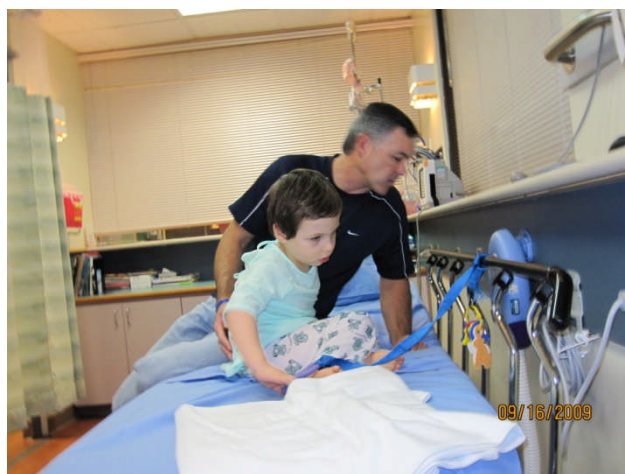
our medical records consisted of over 3 file boxes of information, she quickly decided that just a fax explaining what I wanted would be sufficient. I was honestly a little sad that they couldn't give us an answer, nor would they let me talk with a doctor. I started to think that they wouldn't be the place either. But, I reminded myself to stay positive and your father and I put together a 1 page fax and sent it on. I recall simply asking them to please consider helping you and to consider what it would be like to be a 4 year old who couldn't talk, walk, or even see very well. I get tears in my eyes when I re-read that fax. I was desperate to find a chamber for you and had started to feel it may be our last chance to find HBO treatments here in Oregon.

A few days went by and I lost hope. I started to call clinics in California – down by where my sister lives in Southern California. Then, in the midst of my continued phone calls and search, the phone rang and Bend Memorial Clinic said that Dr. Pinnick would like to meet with us. You have no idea how excited I was just to get a chance to meet with the Doctor there. The appointment was about a week away, and it was all I could think about. So, the day arrived and we drove over to Bend to meet the Doctor. Dylan, what you may not know when you are reading this later in life, is that HBO treatments are still considered 'off-label' for children with CP. It isn't a treatment that is recognized by Medicare and Medicaid to help a condition like yours. Your father and I, along with a lot of other parents like us, are hoping to help change that. We believe in thinking and working 'outside the box' and we know that if we have a chance to make a difference in your life, it will not be with just traditional therapy. We believe that if enough parents like us can show that the treatments are helping our children, then we may be able to 'mainstream' these therapies for all children – not just you. Fortunately for us, we found the one place in Oregon that was willing to help us get you Hyperbaric Oxygen treatments.

So, we are now living in Bend during the week and driving home on the weekend. When we started HBO treatments the 3rd of September, we didn't really know exactly how we were going to make all this work. We just knew that you needed these treatments and we would do everything to make them happen for you. The first and second treatments were a bit rocky and you had trouble clearing your ears. So, back to Corvallis we went to get ear tubes put in your ears to help you equalize the pressure.

With ear tubes in, we were now ready to return to Bend to start back up again. On Monday, Sept 21, we tried again. Going to depth wasn't any problem for you, but coming back up from depth caused you discomfort and you cried for quite some time. Well, off to see the local ENT and have the tubes checked. With a clear report from the ENT doctor, we returned on Sept 24<sup>th</sup>, and your dad went into the chamber with you. You reacted a little when the pressure changed to bring you back up from depth, but I think you are use to it now. It has pretty much been smooth sailing since, and have only missed one day in the chamber since. Your father and I trade off going in the chamber with you, and you really enjoy having us all to yourself for that almost 90 minutes each morning.

While in Bend doing treatments with you, we had a temporary place to stay for the month of September, but we



*Dylan waiting for ear tubes –  
he and dad are looking for trouble.*

had to be out of it by September 30. When I started looking for a place to rent in Bend, I learned that everyone wanted a 6 or 12 month lease – and the rents here were much higher than we had planned. We believe we need to get HBO treatments for at least the next 6 months (120 of them - minimum), but because things had started out a little rocky with the treatments, we didn't feel we could afford to sign a 6 month rental lease, and then have something come up with the treatments that could potentially be a show stopper for us. We intend to move to Bend, but for now, while we are doing these treatments and looking for work here, we didn't feel it was financially possible for us to be locked into a lease. Also, because we need to raise money for the treatments and the place to stay, I also needed to find a place that would allow me to put our rent on a credit card, and that seemed a little tough to find.

Someone at your school suggested I contact the Ronald McDonald House in Bend and see if we could stay there. I had thought the RMH was only for critical children and really didn't know much about how they operated. Your father could see the huge relief in me when they said that they had room and we could stay there. So, on Sept 30, we moved to the RMH and have been there almost a month. Over the last few weeks, it has become very clear to me that we are meant to be there with a lot of these young families that are also staying there. Most of the families there have small babies (preemies) in the St. Charles NICU. Everyday the other people in the house say HI to you, and you cheerfully greet them... sometimes with your "I Tigger", or sometimes with just your cute little smile. You often bounce around in your wheelchair as you smile at them. You recently changed your name to "Tigger" and will correct us if we call you anything else. So, as you wish, we have all started to call you "Tigger".



Several of the families have commented on what a happy little guy you are. I bet that they have all learned something about life watching you enjoy each day – just the way you are. They know we are working to make your life better and allow you to enjoy life like a normal little 4 year old. I know that you, like us, look forward to the day that you can walk and run on the playground like the other children your age. Tigger, your father and I are dedicated to making that day happen for you. I know it is clear to you that our daily routine is focused around your schedule, and what we are doing to help you. You are incredibly attached to both your father and I.



*Mom & Dylan in the  
Hyperbaric Oxygen Chamber*

Each week we drive home on Friday after your HBO treatments, and then return to Bend on Sunday. We do your Oxygen treatments every morning at 7:00am and are finished by 9:00am. Yes, you are a morning person, and you LOVE that we all have to be up by 6:00am. You cannot wait to get out of your crib and destroy the play area we have for you in the room.

There is a huge benefit to being finished with your HBO treatments by 9:00am. That has given us the incredible opportunity to do other therapies with you, and enroll you in school in Bend. We love your teacher and the others in the classroom. You have also met some other pretty neat therapists. You are now getting speech therapy at St. Charles

and you also get to see a physical therapist, Georgia Merrifield, who is very well known here and is doing PT and also HIPPO therapy with you. You got to go in the pool with Georgia last week, and this



week you get your first time on a horse with HIPPO therapy. I know you are going to love it. Back home in Corvallis we have been doing Feldenkrais therapy with you with Christine Dopke – I think that she has adopted you as her child. You loved going there, but now that we are in Bend, you don't get to see her every week. This last week, Christine was in Bend finishing up her training, and she arranged for us to bring you to her school to be the 'demo' for the teacher, so all the other students could see him working with a child. Well... because of Christine, this last week, I got to meet a young man who lives here in Bend that also does Feldenkrais, and he is going to call me and see if we can get you in to see him also. There are great services here for you, and I believe we need to find a way to stay here.

By the end of the week, you will have had about 30 Hyperbaric Oxygen Treatments and we are starting to notice some very nice changes. You are talking more and more everyday and your enunciation of these words just keeps getting better. Your favorite words are now Doctor, Tigger, and Cleo (our friend Brad's German Shepherd). Since you have met Cleo, every dog you see is now "Cleo" and you won't even say the word dog, it's just Cleo. You have been crawling all over the Ronald McDonald house lately, just checking out the place. You seem to really like to be by the front door. Your dad and I were talking, and we realized that your balance and coordination are starting to improve. We have an incline gymnastics mat in our living room in Corvallis that you crawl up and down. When you crawl up your mat now, it is much smoother than before and you are not stopping in the middle, or falling as much to each side on your way up. On the way down you just cruise to the bottom and keep going (in the past



you would lose strength in your arms and often nose dive into the map). Your teachers and the people at the Ronald McDonald house comment all the time how much improvement you are making on a daily basis, especially in your speech.

You are such a trooper and seem to take in stride all that we are doing with you. You do know when we are going back to your home in Corvallis and the car rides back each week have become pretty smooth sailing for you. When we pull into the driveway, you get so

excited – no I mean EXCITED!! You are jumping around in your car seat and can't wait to get into the house. You start giggling and laughing. This state of euphoria seems to last almost an hour. You love coming back to your house, all your toys, your therapy equipment and your ball pit. Many times on the way home, you will say "ball pit" over and over. And when we get you home, you crawl in to our bedroom where your ball pit takes up most of our room, and you can't wait to get in and throw the balls out. Dylan, you do really well no matter where we take you, but you love your home and all the things that we can do with you there. Our home is currently the best therapy studio there is for you. We have a table with bars so you can pull up and learn to stand and cruise, we have an incline mat that you crawl up and roll down, we have a harness that attaches to our ceiling, and you love being in the harness and experiencing being gravity free.

The last several months has been very hectic getting your health insurance changed, so we could get medical treatments for you while we are in Bend, setting up therapy evaluations and getting the



insurance to pre-authorize visits. We have now got you into the daily therapies that we feel are important for you. Although I never stop researching what is out there, for now, I believe we have reached a landing spot, and I took a deep breath (sign of relief) as I wrote this to you.

Today we are just taking one day at a time. We are committed to completing at least 120 treatments at Bend Memorial Clinic and doing whatever we can to help them get Hyperbaric Oxygen treatments as a mainstream treatment for children like you. I believe you are the youngest little guy to be seen in the BMC chambers, and also are the first to drag someone in the chamber with you!! Bend Memorial Clinic & Dr. Pinnick are doing an amazing thing for you. They have never treated a child with cerebral palsy in their chambers, and have

chose you to be their 1<sup>st</sup> child. That is an incredible honor for all of us.

I have heard that they have started a foundation to purchase a chamber mostly for 'off-label' use. I think the parents of a former patient, Summer Stiers, who also did 'off-label' Hyperbaric Oxygen Treatments, started the foundation in honor of their daughter who Dr. Pinnick also treated. Dylan, my dream is that we can help them get that chamber. I can only imagine how many children like you, or people like the young lady name Summer, that chamber could help.

Our next step is to raise money for your treatments as we expect your insurance won't cover them. We are already seeing changes in your speech and your cognitive abilities and we feel we should not stop before we have done at least 120 treatments. Although we are going to try to get your insurance to pay for your visits, it is basically out of the scope of covered procedures and if I am successful in getting them paid by insurance, it will probably only be after a long fight, maybe including taking our appeals to court. I know we need to pay for the initial treatments in order to be able to create a 'case' to present to the insurance to prove they are helping you. I intend to stay the course with this, as more than just you could benefit if we are successful in getting insurance to pay. I may never win the battle with the insurance, so we have set out to raise all the funds needed to continue your treatments. It is our hope that if we don't need all of the funds we raise because the insurance does pay, we would like to donate the additional funds that are raised to the foundation that Summer's parents started.



Dylan, we are almost to the end of the year 2009. Today, HBO treatments are making a difference in children with Cerebral Palsy and also Autism. I don't know what it will be like when you or your children read this many years from now. We have major wars going on in Iraq and also Afghanistan. The Military has started to do HBOT treatments for the soldiers that are returning from war with TBI

(Traumatic Brain Injuries). We are just now learning that HBO is an amazing treatment that could benefit all children and adults that have some kind of brain injury by getting more oxygen to the idle or dormant parts of their brains.



Through years of research, it has been our conclusion that there are two really big things that can be done for cerebral palsy – things that have the chance to help you make big leaps in your development. We are blessed to have been able to do both of those things for you this past year – Stem Cells and Hyperbaric Oxygen.

Dylan, wherever this journey with you takes us, your father and I will **always** be by your side. Some days we will be beside you, and some days we will be carrying you, and challenging you to the next stage of development. But we will always be there with you. You are an incredible gift to us and everyone in your life.

Your father and I are sharing our letters to you about your journey via your blog, so that other parents can learn along with us and maybe one will help that parent who isn't sure where to start when they hear the words 'cerebral palsy' from their child's doctor for the first time. I believe that special children, like you, come to our homes to teach us, and it is with open hearts that your father and I are learning from you.

Tigger, we are proud to call you our son, and you have greatly enriched our lives.

I love you,  
Mom

[www.ALittleBoysJourney.com](http://www.ALittleBoysJourney.com)

Letters / Blogs to Dylan written by Jinger Cain