

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO	DATE
Myers / Waldrep / Platt	6-23-10

DIRECTOR'S USE ONLY		ACTION REQUESTED	
1. LOG NUMBER	100499	<input type="checkbox"/> Prepare reply for the Director's signature	DATE DUE _____
2. DATE SIGNED BY DIRECTOR		<input checked="" type="checkbox"/> Prepare reply for appropriate signature	DATE DUE <u>7-2-10</u>
		<input type="checkbox"/> FOIA	DATE DUE _____
		<input type="checkbox"/> Necessary Action	

APPROVE	* DISAPPROVE (Note reason for disapproval and return to preparer.)	COMMENT
<p>4. Tan - Sam + I are trying to figure out what are options for her. I've requested medical records for the mom.</p>		

Brenda James - Please log - thanks, Fwd: FW: Meredith Hallasy ~ Website email from Amy Hallasy

From: Bryan Kost
To: Brenda James
Date: 6/22/2010 11:13 AM
Subject: Please log - thanks, Fwd: FW: Meredith Hallasy ~ Website email from Amy Hallasy
Attachments: Our Invisible Daughter.doc

RECEIVED

JUN 22 2010

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Bryan Kost
DHHS Senior Consultant
803.898.2865
cell- 429.3201
kostbr@scdhhs.gov

>>> Vivian McDowell <VivianMcDowell@sccenate.gov> 6/22/2010 10:55 AM >>>
Hey Bryan,
Are there not any facilities in SC that are available for their child?
Thanks,

Vivian B. McDowell
Office of Senator Danny Verdin
803-212-6230 (o)

From: Senate Agriculture Committee Mailbox
Sent: Tuesday, June 22, 2010 8:33 AM
To: Vivian McDowell
Cc: Gene Hogan
Subject: FW: Meredith Hallasy ~ Website email from Amy Hallasy

From: Hallasy@charter.net [Hallasy@charter.net]
Sent: Tuesday, June 22, 2010 7:39 AM
Subject: Meredith Hallasy ~ Website email from Amy Hallasy

I know I did not get a response from you the first time, but I thought you may be interested in an update. Attached is my original emial about our daughter. Hello, I know many of you have been praying for Meredith. We appreciate it so much. It is honestly sometimes hard for me to pray. I suppose I am tired, bewildered and very, very sad. I know God is there and that I just need to go along for this ride. It is sometimes harder to trust than other times. Anyway, Meredith is back in the hospital. We took her on Monday evening. She had several nights of not sleeping and keeping our entire family awake by shouting. She shouts quite a bit! She talks to people that only exist in her head. She carries on full conversations with them at times. It is really hard to explain. She still responds and talks to us as well. She has been eating well until yesterday. She is walking, using the bathroom, and even playing a little bit. Everyday, actually every hour are different. She changes and so to the symptoms. It is so hard to understand, because she is so different than she was a year and a half ago. I heard yesterday that our insurance company (Blue Cross Blue Shield) probably isn't going to approve Cumberland Hospital.

They suggest that we put her in a long term residential home. In other words, they think we should just let her rot somewhere and be done with it. How can they be so callous? We had a child that was very functional and something has happened in her brain that is causing all of this. Her doctors are outraged that the insurance company would suggest such a thing. They believe she needs to be in a medical environment where she can be observed and treated around the clock until we can get her back to her baseline. Greenville, nor the state of South Carolina have anyplace that is willing or able to provide this service. Believe me, I wish they did. I am not thrilled about the idea of leaving my baby 6/2 hours away! We also have heard that South Carolina Medicaid will not pay for Cumberland. Actually, they do not pay enough for Cumberland to accept it. (At least that is what I have understood.) I guess it is time to call in my senators and representatives again! I need some pull from somewhere!!! You all take care. Pass this on to anyone that is interested. Thanks, Much Love, Army

Amy Hallasy
5 Crossvine Way
Simpsonville, SC 29680
864-430-1997

Bc/BS - case manager -

- DDSN - case worker - applied for CLTC
"been a nightmare"

→ MR, Autistic, Psychotic

- Greenville hospital - Bill Schmidt

developmental pediatrician
neurologist
psychiatrist
etc

needs to be in a facility that specializes in neurological
+ psychiatric [MR/psychiatric]

- Cumberland hospital - Virginia
New Kent, Virginia
Marcel
in the worker

Medicaid # 4833751201

Deborah
McPherson
retiree?

Our Invisible Child

Our daughter, Meredith, was born at Greenville Memorial Hospital on July 27th, 1996. She was born 14 weeks prematurely with a birth weight of 1 pound 5 ounces. She had many complications in the Neonatal Intensive Care Unit where she stayed for 107 days. Among those complications were a grade IV intraventricular hemorrhage, and serratia meningitis. Those two complications were the turning point in her life.

An intraventricular hemorrhage is somewhat like a stroke. It can affect motor skills and speech like a stroke does. Serratia meningitis is something that you acquire. Serratia is an intestinal bacteria. The most likely way that Meredith acquired serratia meningitis is from someone that was handling her. In other words, someone didn't wash their hands adequately.

The meningitis eventually led to hydrocephalus. This was our first encounter with an insensitive and pompous health care provider. I, as her mother, recognized that Meredith's head was swelling and that she had a dreamy look in her eyes. I called it to the attention of the nurses and doctors on staff. The nurses agreed with me. I asked for an ultrasound of Meredith's brain. The doctor determined that we could wait another 5 days before getting an ultrasound. It was too inconvenient for him to order an ultrasound at the time. Of course when the ultrasound was performed 5 days later, and Meredith brain had been under tremendous pressure, that doctor had the nerve to look me in the eye and say, "her brain was all messed up anyway." No, I am not kidding. Those were his words. That was our first encounter with a medical professional that put his ego and authority over the care and treatment of his patient. (Dr. David Wells)

The next time we ran into a problem with an arrogant doctor was when Meredith was about 14 months old. I was having a terrible time getting her to eat. I was growing more and more concerned about her lack of caloric intake. Dr. Bill Wiley's response was that I was being an over-reactive mother and that Meredith would eat when she was hungry. I knew he was wrong! Within a couple of months Meredith was hospitalized and was diagnosed with failure to thrive. We ended up with a feeding tube for the next seven years.... You know what?She never got hungry!

Since that time, Meredith has grown and loves to eat. She likes to play with baby dolls. She is the queen of monkey bars, swing sets, swimming and she even likes to roller skate and ski. Meredith loves books, movies, live theater, camping, coloring, sewing, and just being a kid. She is very fashion conscious and loves to look pretty.

The reason I am writing this is to tell you about our latest encounter with the medical system. About a year ago, Meredith suddenly quit eating, drinking and talking. This happened in one day. One day she was fine and the next she shut down. She was mute and did not eat or drink for 30 days. She was completely withdrawn and non-responsive. Of course after a few days I became very alarmed. I took her to the emergency room. She was admitted to the hospital, only because I insisted. She stayed in the hospital for 8 days. During her stay, she received IV fluids. The doctors kept saying this was a behavioral problem. One doctor actually came into our room and said, "I don't do this type of kid. I don't deal with kids that have mental retardation and emotional problems." We were sent home without a plan and with absolutely no hope. We begged and begged for a psychiatric consult. The psychiatrists wouldn't come to see her because she is mentally retarded. "They don't treat people with mental retardation."

We were stunned! Isn't that against the law? Can a doctor deny care to someone on the basis of their IQ? Don't we have laws that protect people with disabilities? What about the Americans with Disabilities Act? What about Public Law 94-142. So in other words, children with disabilities are guaranteed a free and appropriate public education and access to all public facilities, but they are not guaranteed appropriate medical care. I am not even talking about free medical care. We have private insurance AND Medicaid for Meredith. We would give all that we have to help our daughter. In this country can someone be denied something as basic as medical care based on their IQ?

Since Meredith's admission to Greenville Hospital in May of 2009, it has been entirely up to me to coordinate research and find help for her. It seems as though her doctors have all thrown up their hands and tried to pass the problem on to someone else. The neurologist says it is a psychiatric problem. The psychiatrist says it is a neurological problem. One psychiatrist says that this is all because Meredith doesn't want to grow up, and this is her way of controlling her environment. Tell me when the last time you knew somebody that would refuse to swallow their own saliva because they didn't want to grow up. The pediatrician and developmental pediatrician have admitted that they do not have a clue. While all of these people have been compassionate, none of them have been able to offer any type of help or plan.

We have had an entire year of jumping from one anti-psychotic drug to another. Each of these drugs has had horrible side effects. She has experienced incontinence, stiff legs, the inability to swallow, torticollis, mutism, insomnia (no sleep for 7 consecutive days), mania, hallucinations, facial pulling, eye movement irregularities, and many other

things that are impossible to describe. Her psychiatrist has been trying to find the right medications to help. Perhaps psychosis isn't even the problem!

However, two weeks ago, Meredith was readmitted to the hospital. She was in a tremendous amount of pain from a reaction to a medication. Her CPK levels were elevated and her muscle tissue was beginning to break down. Her legs were stiff and she could not walk at all. She cried and cried from the pain, the fear and the frustration.

While in the hospital, she once again got IV fluids and medications to help her legs relax.

It was truly a miraculous act of God that she was able to get a psychiatric consult while she was in the hospital. I think the only reason they came to see her was because the blood work clearly showed that she was having a reaction to the psychiatric medications.

The entire nursing staff was stunned that psychiatric services agreed to consult in Meredith's case.

You may ask why her psychiatrist didn't take care of her in the hospital. Good question! Private psychiatrists don't have hospital privileges and don't see or take care of their patients in the hospital. Absurd if you ask me...especially if the reason they are there is because of a psychiatric drug....

After 4 days of hospitalization, we were discharged. Meredith still could not walk and she continued to cry a lot, but her blood work was looking better. I had to insist on a wheelchair to use at home. We were going to be discharged without help, without a plan, and no way to ambulate. The social workers told me that I should contact DHEC for help.

(Here is my commentary on DHEC. What do they do? It has been our experience over the years that DHEC is really good at saying, "We don't do that or we

don't have the funding for that." There is a several year waiting list for every service they do provide. In my opinion, DHEC has enough money to hire a couple of people to answer the phone and tell people they don't have any money or personnel to do "that". At one time we did have 6 hours per month of respite care. That lasted less than a year and it really wasn't enough to pay anyone to provide care. We had to match the amount ourselves. Now, of course there isn't any money for that either.)

Once we were home from the hospital, Meredith continued to have difficulty walking and seemed to get stuck in weird positions. Her arms, head, legs and neck were all involved. I took her back to the emergency room after being home for 3 days. We spent the entire day in the ER. She was given something to relax her and also was given IV fluids. Once again we returned home without a sense of direction.

By the middle of this past week, I was really beginning to freak out. She was so very, very sad. My beautiful child was turning into a wheelchair bound, mute, catatonic, invalid. This is not okay! Our psychiatrist was out of town for the week and his office staff and partners were completely useless. They did not return my phone calls or see the urgency in this matter.

Finally on Wednesday of last week, I called her pediatrician, Pam Chivers. I told Pam about the situation and the increasingly weird behaviors that Meredith was having. I told her that I wanted her evaluated and possibly admitted to a psychiatric hospital as soon as possible. Pam agreed that this would be appropriate. She took 3 hours out of her day to contact all psychiatric facilities within 200 miles of us. Over and over again, she was told, Meredith doesn't meet our patient criteria. We don't treat children with mental retardation. How is this possible? Again, how is it possible that someone can be denied

treatment based on IQ? The director of the children's psychiatric services at the Medical University of South Carolina (Dr. Koval) did agree to look at Meredith's records. After looking at her records he determined that she was having seizures and that she should be admitted to Greenville Hospital under neurology with a psychiatric consult. How do you determine that a child is having seizures without seeing the child or even speaking to her doctor? He told his nurse to call the pediatrician to deliver this diagnosis. Children that are having seizures do not behave the way Meredith has been behaving.

We immediately went to the neurologist. He did an EEG and some blood work. Nothing was found. We asked our neurologist to call Dr. Koval at MUSC and to tell him that Meredith was not having seizures. Dr. Koval listened, and then said, "She doesn't meet our patient criteria." Once again, denied treatment.

As of now, we have inserted a feeding tube into Meredith's nose. We have to keep her hydrated and fed this way until someone is willing to help us. She cannot play. She barely acknowledges our presence and she is without joy. She sits in a wheelchair with her head torqued to the side, and her legs stiff and rigid. Meanwhile we wait and wait and wait for help that never comes.

Tell me, where does someone go that is mentally disabled and needs psychiatric help? Are they destined to progressively worsening mental illness? How are we able to turn our head and ignore these people? Children like Meredith cannot advocate for themselves. They don't have the mental ability to understand their situation. They are fearful and hurting and we allow our system to continue to abuse and neglect them. I thought that cruelty and discrimination were supposed to be things of the past. We abolished slavery. Gays and lesbians have rights. The Americans with Disabilities Act

was passed. Racial profiling is illegal. We are a country that is enthusiastic about the rights of everyone. “Everyone” should also include children and adults with mental retardation, autism or any other type of disability that prohibits them from being able to self-advocate. Our current psychiatric system is cruel, neglectful, and inhumane to these individuals.

In God’s eyes, Meredith is perfect. He wove and spun her into His absolutely perfect creation. She is among us for a reason. Perhaps she is here to open our eyes and make us see the invisible children in our society. Open your eyes people. Look at HER. She is real. She is alive and she is hurting!

Please forward this to anyone that would be interested in making this issue public. Send it to congressmen, hospital administrators, doctors, autism awareness groups, Americans with Disabilities organizations, lawyers, parents of disabled children, teachers and social workers. Send it to anyone that might care.

By the way, Greenville recently had a teenage boy jump out of a moving ambulance. Guess what! He was mentally ill and had autism. He had not been receiving adequate medical care. He is now dead.

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TO <i>Myers</i>	DATE <i>6-23-10</i>
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1. LOG NUMBER <i>1011499</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR _____	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>7-2-10</i>
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