Teri Broadstreet, parent

Public Comment to the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children

June 8, 2004

March 12, 2004

Ms. Elizabeth M. Duke
Administrator
Health Resources and Services Administration
5600 Fishers Lane
Rockville, Maryland 20857

Dear Ms. Duke:

I am seeking your assistance to make the enclosed material available to the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children.

The information provided by Mrs. Teri Broadstreet is about her experiences following the birth of her daughter, Julie. This mother alleges that the pediatricians were negligent in the care of Julie and the lack of parental resources compounded her frustration. Julie had multiple abnormalities that would have been recognized with an early diagnosis identified in newborn screening.

Mrs. Broadstreet would welcome the opportunity to answer questions from a mother's perspective if the panel would find it useful. She is well spoken and communicates well. Her contact information is shown on her correspondence.

Please respond to our office in Washington, D.C. Your questions may be directed to Mrs. Jane Miller of my staff at (202) 225-3065.

Sincerely,

Howard Coble
Member of Congress

HC:jm

Enclosure

Teri D. Broadstreet

February 3, 2004

Howard Coble
Member of Congress
2468 Rayburn Building
Washington, DC 20515

Re: Neglect of Proper Medical Care

Dear Mr. Coble,

I am writing in reference to the neglectful medical care my 6 year old daughter received from birth, September 30, 1997, until February of 2002, from a local physician. Since being removed from their care, my daughter has been diagnosed with an extremely rare form of Trisomy 13 Genetic Syndrome, "Mosaic Trisomy 13". This has brought along with it, enumerous disabilities and abnormalities to include: Atrial Septal Heart Defect, Duplicated Right Kidney Collecting System, Global Sensory and Behavioral Impairments, Polydactaly, and Developmental Delays.

From birth Julie presented with many physical indicators symptomatic and inherent, not only to her disorder, but to a Full Blown Trisomy 13, as well s many commonly known Genetic Syndromes. In addition, she was at immediate High Risk, due to the fact I was of advanced maternal age, turning 39 years old October 14, 1997. At birth she presented as: Cyanotic, Required Resusitation, Respiratory Distress, Nuchal Cord X2, Transverse Simeon Palmer Creases, Polydactaly, Microcephaly, Epicanthal Folds, Ventral Hernia, Hemangiomas on her Forehead (with an unexplained Knot and Bruising), Broad Falt Nose, Small Slanted Close Set Eyes, Lowset Ears, Thin Flat Upper Lip, Abnormal Flexion in her Fingers, Couldn't Suckle, Very Weak Cry, Below Average Birth Weight, an Undiagnosed Atrial Septal Heart Defect, and her Undiagnosed Kidney Defect. I am certain there must be other indicators that as just an "Uneducated Mon", having to decipher the Medical Jargon word by word, I haven't determined as yet.

Julie was seen by Dr. Winters and Dr. Reedy of Archdale Pediatrics, Archdale, NC from birth until she was 5 years old. My family expressed great concerns, even perfect strangers approached me in department stores stating, "She's so cute, does she have Downs syndrome?" I entrusted my child's complete life and total care to these physicians. Julie remained at and below 5th % height and weight from birth. She continued with eating issues (so vaguely recorded in her medical records "baby doesn't like formula"), excruciatingly painful constipation along with mysterious high fevers blown off as viruses, that I attribute now to her Kidney Disorder (presenting the exact same symptoms), dysmorphic features, motormental retardation, turning blue to the point of passing out when crying (Dr. Winters laughed off, telling me she hyperventilated, also stating her skin tones were just going to have blue undertones because she was a redhead), major eye issues (her first prescription was 6.5), developmental and behavioral issues etc. . . Despite my many concerns, these physicians diagnosed her as completely normal, never interveining or referring her to higher levels of medical care such that major medical centers like Brenner's Children's Hospital. Wake Forest Babtist Medical Center, or Duke University can offer, disregarding every single one of my concerns. I've since discovered there was chatter amongst themselves, never in my presence, along with questionable xrays made the day Julie was born, with much vaugness, and many discrepancies in her medical records. How these physicians were totally and absolutely negligent in my child's care is appalling and completely departs from acceptable and prevailing medical practices. I will establish their negligent treatment produced an extremely precarious safety risk, for my daughter's health and life, much greater than any prevailing treatment they should have provided.

I sought outside intervention through the Randolph County Health Department whose Nurse, Wendy Boggs RN, immediately observed dysmorphic features, as well as abnormalities in Julie's eating, gait, eyes, behaviors, delays etc. . . She immediately reffered her for evaluations at Developmental Evaluation Center in Greensboro, NC and to an ophthalmologist. Dr. Ted Anderson at DEC, also, immediately observed her differences and reffered her for genetic testing. This resulted in her initial diagnoses of "Mosaic Trisomy 13 since birth. As a result, because of High Risk with Trisomy 13, Julie was refered for further testing of her Brain, Heart, and Kidneys, where I also, initially discovered her Atrial Septal Heart Defect and Kidney disorder. Julie was 5 years old. As her health continued spiraling downward I requested all of my daughters care to be transferred to Wake Forest Babtist Medical Center. Here, I thank, Dr. Joel Hutcheson Pediatric Urologist for giving my child the Gift of Life. He performed a Reimplantation of all of Julie's Ureathera's,. after discovering she had become resistant to 9 different antibiotics and developed an E-coli Infection, then a major Staff Infection due to her Kidney disorder. Urine was improperly routed, causing pooling and stagnating in her body since Birth. By the Grace if God, Dr. Hutcheson didn't find as much kidney damage as he had expected to find in a child that had been neglected for so long. Had this precarious, negligent, treatment continued Julie's kidneys would have shut down and she would have died. I am horrified in knowing, had my child died during these physicians care, Archdale Pediatrics, from birth until 5 years old, I would never have known the truth, as I suspect has happened to many families past, and ongoing (SIDS I suspect in my cases for example). Although we face many other issues, for the first time ever, Julie is currently symptom free, medicine free, and pain free, beginning to grow and thrive. She is an absolute joy and miracle child, despite her odds. A child born with a Full Blown Trisomy 13, if she survives to become full term, 85% of these babies, do not survive 6 months old. Prognosis for Julie is unknown.

I feel my child has not been rendered proper evaluations, treatments, services, and habilitations due to the fact I must use the Medicaid System to fund her medical care, and, these physicians saw my child as

a lost cause with no hope. With malice, on Julie's last visit to Archdale Pediatrics, Dr. Reedy beligerantly told me I was wasting my time, she didn't need genetic testing, didn't have a hernia, she was oppositional defiant and ADHD, there was no hope for my child, and, to be honest she had more problems than he knew what to do for. I threatened him that Wendy Boggs, RN for the Health Department would go over their heads if necessary as she had told me she would do so if she had to. At this point he angrily told me I would get them in the mail, and again I was wasting my time, as he slithered out the door. Dr. Chamberlain, Julie's current pediatrician, upon first glance of her medical records, stated, quote "If I were you, I would be madder than hell!" Dr. Anderson DEC, and Dr. Jewitt, Geneticist, WFU have also stated they don't understand how this happens time and again. I have discovered a whole society of families silently suffering as mine has through Networking and Support Groups. In addition, I've discovered a, "silent conspiracy", amongst physicians, covering each others tracks. As the parent of a precious little one, we endure enough pain and dejection at the loss of our dreams for our children. Small milestones become great triumphs.

I am seeking your assistance to present a bill to Congress to mandate more extensive evaluations of especially High Risk newborns. This disgusting, negligent practice must be stopped. Doctors must not be allowed to so arrogantly play "God", with our innocent children's lives. They must be made accountable to someone. I can find no laws to protect our children. A simple blood test at birth would prevent must needless pain and suffering, but, ultimately death.

I would appreciate an expedited reply on this matter. Thank you for your time and interest.

Sincerely,

Teri D. Broadstreet
"Just A Mom"
Supporting Medical documentation and photos enclosed.