CLIENT: Veronica Roman
TELEPHONE PRE-EVALUATION: July 9, 2002
DATE OF EVALUATION: July 17, 2002
RE-EVALUATION VIA TELEPHONE DATE: April 29, 2003; August 12, 2003 and February 17, 2006
DATE UPDATE REPORT INITIATED: February 28, 2006
REPORT FINALIZED: March 21, 2006

Veronica Roman is a Caucasian female, age 5 years and 11 months. The initial evaluation of Veronica was conducted at her home in Charlotte, North Carolina in the presence of her parents Joseph Roman and Mary Roman on July 17, 2002. Since that original evaluation numerous telephone conferences have been conducted with her mother Mary, in order to track Veronica's development and maintain current data within her file. Telephone conferences were conducted on April 29, 2003; August 12, 2003 and February 17, 2006.

The most recent telephone conference on February 17, 2006 was initiated in preparation for the upcoming trial. A telephone conference was conducted between myself, Mary Roman and one of the counselors on my staff, Kay R. Brown, CLCP. All of the original clinical interview and history data, along with the data collected during the 2003 telephone conferences, were reviewed within the context of this telephone conference to determine any changes. The data collected during this update clinical interview and history was used to update the Life Care Plan prepared for Veronica September 27, 2002. In addition to the new data collected during the interview, consideration was also given to the research literature and clinical practice guidelines regarding cerebral palsy, developmental delay and hearing impairment, promulgated by multiple sources and cited in the updated Life Care Plan. Correspondence has again been issued with her treating physicians, although at this point the only new response we have received has been from her pediatrician Dr. Jamie Noor. As is our usual and customary practice, this Updated Life Care Plan has been reviewed by our consulting physiatrist, Andrea Zotovas, M.D. All of these steps are taken to help in establishing the medical foundation, in addition to the case management and Life Care Planning foundations, for the plan. This report will serve to update you on Veronica's current status.

Demographic Information:

Veronica continues to live with her parents in Charlotte, North Carolina. She is now 5 years and 11 months old and attending kindergarten at Williams Elementary within a special education class. Her weight has increased to 40 pounds.

Rehabilitation Program(s) [In/Outpatient Since Injury]:

At the time of the update telephone conference on 4/29/03: Veronica's therapy program continued through the Avalanche Developmental Group with OT 2 X / month; ST 1 X / month, PT 1 X / week and ST 2 X / week. These began on 4/14/03. She had private PT at Mecklenburg Regional with Kiera Smith 1 X / week. She had Auditory Verbal therapy with Jazmine Wyatt 1 X / week. Veronica had vision therapy one time per month with Sarah Randley, who is with the Mecklenburg pre-school program. She was no longer having speech therapy at the school for the Deaf.

At the time of the update telephone conference on 8/12/03: Veronica had not had any hospitalizations, VP shunt revisions, seizures or complications with her Cochlear implant. She did undergo a trial for a Baclofen pump in June 2003. She had to have several lumbar punctures (9) and was very upset for a few days following procedure. She is scheduled to undergo another trial on 8/14/03 at River Medical Center. Dr. Andrews is the physician.

She continued to attend Avalanche Developmental Group 5 days/week from 8:30 - 2:30 PM. She received PT and OT at the center and was scheduled to begin ST that week or next week. She continued to receive PT 2X/week privately at Mecklenburg Regional Medical Center, ST once per week for one hour and vision therapy in their home or at Avalanche Developmental Group.

She underwent Baclofen trial in 6/03 and was scheduled to undergo another one on 8/14/03.

At the time of the update telephone conference on 2/17/06: Baclofen pump was placed Fall of 2003. She did have problems initially with infection and catheter placement requiring several revisions, but it is now functioning well and seeing good results. The last problems with the pump were in 2004. She did have a myelogram in 11/2005 and required a lumbar puncture but that was the last.

She remained at Avalanche until she started kindergarten in Fall 2005. She goes to Williams Elementary. School is supposed to be getting PT 2 X / week, but the therapist left so she is not getting it now. They are trying to replace PT but they have not had any luck. OT 2 X / week for 30

minutes individual, ST 2 X / week 30 minutes - one session individual, one session group. Auditory verbal therapy 1 hour per week. Vision therapy 2 X / month 30 minutes each. She attends school Monday, Tuesday, Thursday 10 - 2:30. Wednesday and Friday 8 - 2:30. Mom transports her to and from school.

Private therapy at Mecklenburg Regional. PT 2 X / week for 1 hour each. Auditory verbal therapy from Peeds Speech and Language, 1 hour per week.

Chief Complaint(s):

Disabling Problems: (By client/family history and report. No physical examination occurred):

Update 4/29/03: Her disabling problems remained the same. She continue to display neurological devastation. She was no longer on Reglan for reflux, as her reflux had improved. She had not required a shunt revision since April 2002. PT had helped Veronica make some improvement in her ability to move her left arm. She was also less fussy during PT. Although her left arm movement had improved, the arm was still not functional. Veronica started using a walker in therapy, but she needed maximum assistance from the therapist. Veronica still would hold her breath and turn blue, but that usually only occurs at night when she is tired. Her vision was tested in March 2003. Her right eye was 20/63 and the left eye needed retesting. Her hearing was tested and she was at the 55dcb level, which was less than needed to be for spoken language. They were unsure if she would get improvement. Veronica startled to loud noises. Veronica had been seizure free and required no additional shunt revisions. She attended the Avalanche Group from 8:30 until 2:30 on Monday, Wednesday, Thursday and Friday. On Tuesday she went to school at 10:15. The family had not used any respite care and they had no attendant care assistance. Veronica sucked her thumb. She held her right thumb out more. She was able to laugh out loud. Her mother felt there had been some improvement in her ability to attend.

Update 8/12/03: Veronica no longer took Reglan as reflux had improved. Height was 37'' and weight was 29 pounds. There were no new complaints.

Update 2/17/06: Veronica continues to have a mild cortical visual impairment and she is getting vision therapy. She does have auditory verbal therapy, private and at school for Cochlear implant training.

She has a Little Magician Stander and this is working well. She stands about an hour a day at school. She can sit independently for 30 to 45 seconds. She can not feed herself. She no longer needs Pediasure supplement.

Spasticity is better with Baclofen Pump. They are now doing bolus Baclofen instead of constant and this has shown improvement in tone particularly in legs.

Drinks from sippy cup with a nipple, but she can not hold the cup independently. No surgery was ever done for reflux, improved with growth and age.

VP shunt in place. No revisions since 2002. CT done annually to monitor.

Vision test yearly, last done in 4/2005.

They are using some respite care occasionally through Ryan Sanders. (xxx-xxx-xxxx). This is a company that coordinates care. This is received through the CAP MR/DD program. They have started to use this more now that Veronica is older, because they need more qualified caregivers, than extended family members can provide. Mary estimates that they use maybe 10 hours a month at this point, so that they can have some time together.

Veronica is no longer holding her breath.

Developmental Delay

Seizure Disorder

Breakthrough Seizures: 2/17/06: Veronica is not having seizures.

Last Seizure: In hospital.

Surgeries

Performed: 2/17/06: She required several revisions of her Baclofen pump.

Anticipated: 2/17/06: None.

Motor Skills

Bring Hands to Midline: Update 8/12/03: Brings right hand to midline more since Baclofen was increased a few months

ago. Occurs mostly when lying supine. Veronica can now purposefully bring left arm to midline occasionally. Update 2/17/06: Same.

Grasp (Left/Right): Update 2/17/06: She still is unable to hold her cup.

Grasp with thumb & forefinger: Update 8/12/03: Right thumb out more now. 2/17/06: Same.

Voluntary purposeful movements (upper & lower extremities): Update 8/12/03: Brings leg up, kicks back and forth sometimes when angry. 2/17/06: Same.

Sit unassisted: Update 8/12/03: Still unable to sit unassisted longer than 10 seconds. 2/17/06: Sits for 35 to 40 seconds occasionally.

Hold head erect: She can hold her head erect for only a few seconds. Inconsistent. Update 8/12/03: Unchanged. 2/17/06: Same.

Roll Front to back: Yes, but not consistent. Being on a soft surface helps. 2/17/06: Same.

Roll Back to front: Same as above.

Pull self upright: Not functional. 2/17/06: Same.

Drink from cup: Not functional. She does sip from a *''sippee nipple if we hold cup''*. 2/17/06: Same.

Drink from bottle: Uses bottle/cup with a *''sippee nipple''*. Stem with two holes in the end from which she sips. Parents hold the cup or bottle for her. Update 2/17/06: Same. 2/17/06: Same.

Tube feeding schedule: Update 8/12/03: Eats soft foods, mashed potatoes, etc. 2/17/06: No longer on Pediasure.

Ambulate: Not functional. 2/17/06: Same.

Assist in dressing: Not functional. 2/17/06: Same.

Perform household chores: Not functional. 2/17/06: Same.

Perform personal hygiene: Not functional. 2/17/06: Same.

Crawl: Not functional. No pre-crawl progression. 2/17/06: Same.

Ascend/descend stairs: Not functional. 2/17/06: Same.

Social Skills

Smile: Update 8/12/03: Now is able to laugh out loud. Does so when being tickled. 2/17/06: Same.

Laugh out loud: Update 2/17/06: She will laugh out loud. 2/17/06: Same.

Dintinguish family from strangers: Update 2/17/06: Can distinguish family.

Demand personal attention: Normally, she will cry and demand attention.
2/17/06: Same.

Cognitive Skills

Imitate sounds: Update 8/13/03: In ST, can make partial moo sound when shown picture of cow. Update 2/17/06: Doing more vocalization on demand.

Talk in 1 or 2 word sentences: Not functional as yet. 2/17/06: Same.

Follow simple 1 or 2 step instructions: Not functional as yet. 2/17/06: Same.

Avoid hazards: Not functional. 2/17/06: Same.

Communicate wants and/or needs: By crying only. 2/17/06: Crying and vocalization sounds.

Attention to task: Update 8/12/03: Can focus for about 10 minutes now. 2/17/06: Same.

Long-Term Care Options

Facility/ Home Care: Preference is to keep her in the home setting. 2/17/06: Same.

Anticipated Treatments: Update 8/12/03: Undergoing Baclofen trial at this time. Update 2/17/06: None anticipated, although at periodic intervals could require revision of VP shunt, replacment of Baclofen pump and replacement of Cochlear implant.

Psychosocial Issues

Patient: Update 2/17/06: Irritability has stopped, except for occasionally when tired as are most children. Basically she is a very happy child.

Family, Emotional Impact on Spouse/Children: Update 2/17/06: They have good and bad days. They function on a routine. Mary has not returned to work. She feels that their relationship is stable.

Physical Limitations

Loss of Tactile Sensation: Update 8/12/03: Not as resistant anymore. Now moves left arm purposefully but not with any consistency. 2/17/06: More responsive now.

Reach: She will only reach out with her right hand. She can reach for a toy and put it to her mouth. This just began about 2 months ago. Since Baclofen dose increased movement on left increased. I observed voluntary opening and closing of left fingers as well as movement/reach of left arm but not to extent of right. Update 8/12/03: Same. 2/17/06: About same, reaches more with right than left.

Lift: Update 8/12/03: Lifting with right arm is not age appropriate. Update 2/17/06: Lifts or holds light objects with right, no lifting with left.

Prehensile/Grip: Fair grip with the right, and minimal on the left.
Update 8/12/03: Same with right hand. Can grip with left hand but does not hold on for long. Update 2/17/06: Same.

Sitting: Update 8/12/03: Able to sit for a few seconds, maybe ten, but not consistently. Update 2/17/06: Sits for 35 to 40 seconds occasionally in therapy. This is not consistent. Does sit in positioning systems.

Standing: Update 8/12/03: She gets upset when placed in stander but calms down and can stand for one hour both at school and at home. Update 2/17/06: Little Magician stander used daily at school and a Snug Seat Wombat seating system at home.

Walking/Gait: Update 2/17/06: Trying her in a Rifton walker in private PT, but she is not taking steps on her own. This therapy has just started about 2 months ago.

Bend/Twist: Not functional. Update 2/17/06: Same.

Kneel: Not functional. Update 2/17/06: Same.

Stoop/Squat: Not functional. Update 2/17/06: Same.

Climb: Not functional. Update 2/17/06: Same.

Balance: Not functional. Update 2/17/06: Same.

Breathing: Update 8/12/03: Still holds breath when upset but not as often. Update 2/17/06: No longer holds breath.

Headaches: Parents are not aware of any problems. Update 2/17/06: Same.

Vision: She has cortical visual impairment, and can see 20/84. Update 2/17/06: Right gaze still strong, but there is some improvement in her left gaze.

Hearing: Bilateral Hearing Loss - Severe to Profound hearing loss bilaterally before the Cochlear Implant. Update 8/12/03: According to last Audiogram- can hear 40 - 50 decibels. She turns to voices. Definitely hears loud sounds. Update 2/17/06: Same.

Driving: Not functional.

Physical Stamina (average daily need for rest or reclining): Update 2/17/06: Up at 6:00 a.m. and goes to bed 6:30 p.m. No naps. Alert through waking hours.

Environmental Influences

Problems on exposure to: 2/17/06: All the Same.

Air Conditioning: No.
Heat: Cannot tolerate heat, becomes very irritable. 2/17/06: Not as irritable, but doesn't like heat.
Cold: Yes.
Wet/Humid: No.
Sudden Changes: No.
Fumes: No.
Noise: Update 2/17/06: She will react to loud noises now.
Stress: Yes.

Present Medical Treatment

Update 4/29/03: Treating physicians remain the same with the addition of Dr. Wade ENT seen 1 X / year. She sees Dr.

Noor, prn, Regina White, MS, CCC-A/SLP 1 X / 3 months; Dr. Nicholas 2 X / year; Dr. Andrews 1 X / year; and Dr. Farmer 1 X / year. Her only medication is Baclofen 15 mg 3 X / day. She has no new equipment.

Update: 8/12/03:
PT at Alamance Regional is now Kiera Smith.
Karen Henderson: Avalanche Developmental Group.
No longer sees Sandy Johnson at School for the Deaf. New therapist is Erin Ryan Ophthalmologist: Dr. Wade Sees once per year. Last visit was in July 03. In March of 2003, right eye was diagnosed at 20/60. Doctor was unable to get reading in left eye and recommended Veronica wear a patch on her right eye to strengthen the left. In July, left eye was improved and doctor thinks Veronica can see out of left eye the same as the right but could not test her that day. She is to return in six months for follow up.
Medications: Baclofen increased to 15 ml 3X/day. Veronica no longer takes Reglan as her reflux has improved.

Update 2/17/06: Sees Dr. Westley Willis, neurologist /3 months; Dr. Farmer 1X/yr; Dr. Nicholas 1X/year; Dr. Noor as needed and Regina White, MS, CCC-SLP/A 2x/year.
Only medication is Baclofen, 2mg/ml, 5 cc X2 a day, prescribed by Dr. Willis.
Orders cables from Cochlear every 3 months for $65.
Wombat Seating System 11/2005.
Therapy Update 2/17/06:
PT 2X/week with Tiffany Duke at Mecklenburg Regional Med. Center OT with Karen Henderson 2X/week at Williams Elementary
ST with Marcie Martin at Williams Elementary 2X/week.
Auditory/verbal therapy with Ellen Knightley 2X/week at Williams Elementary.
Auditory/verbal therapy with Timothy Scarn 336 286-8918 1X/week at Peeds Speech and Language.

Medical Summary

Addendums to Medical summary from records reviewed after initial report released:

ADDENDUM: 11/13/02

CYRA, EMILY M.D.: 10/4/02
Neurological evaluation regarding various neurologic and neurocognitive concerns. Veronica seemed happier and more interactive in the past year. She had been followed by Dr. Nicholas for spasticity and was receiving school based and private PT and OT.

She had some visual difficulties and her visual fixation and following seemed to fluctuate. She seemed more attentive now but did not consistently fixate or follow. She did seem to perceive light and turn toward light.

Veronica underwent cochlear implantation in 5/02. Her parent's related she had been much more vocal since that procedure and was now turning to sound. She looked her parents in the eye, especially if they were speaking but also sometimes when they were not.

She had delay in cognitive/mental development and received speech/language therapy privately. It also helped with feeding.

Veronica's parents described that she was able to turn her head in prone position, but they were not certain whether it was purposeful or positional. She sucked her thumb and got her bottle close to her mouth. She opened her mouth when she saw a bottle. She played switch toys, especially a fan toy. She responded with smiling and laughing to rough-housing and other attention including being held, being sung to, or her mother or father's presence. She responded negatively with grimacing and crying to discomfort, gag reflex, etc.

Neurological examination revealed rightward gaze preference and left cochlear implant. She was responsive to sound and looked toward her father's voice and toward the tuning fork. Facial movements were symmetric, though there was possibly a little nasolabial fold flattening on the left. There was possibility of visual field cut to the left, correlation with right gaze preference and mild positional plagiocephaly. She grimaced and objected with crying to gag. She also resisted examination by reaching with her right hand to push Dr. Cyra away. Her left limbs were stiffer and although she did have spontaneous movement, definite purposeful movements of the left limbs were noted. She did make purposeful movements with her right arms. She was not sure there were any purposeful movements of the right leg. She smiled to her parent's voices and smiled when seeing a bottle and bib presented. Muscle strength was diminished throughout, especially on the left, and her muscle tone was increased throughout, especially on the left. Deep tendon reflexes were also increased throughout, though her lower extremities reflexes were 4+ on the right and 3+ on the left, but 3+ symmetrically in the UE's.

Veronica presented with a combination of features constituting a severe global non-degenerative encephalopathy, apparently meningitis-induced. The encephalopathy encompassed hearing loss, post meningitis hydrocephalus requiring shunting, hypertonic/spastic quadriparetic CP, worse on the left but also affecting right

limbs, cognitive/mental impairment with severe to profound mental retardation, visual impairment probably constituting a cortical visual impairment and history of agitation/personality changes, though the latter had improved lately. She had an effective gag and was able to feed appropriately with safe airway protection. She had been seizure free for more than 2 years.

She anticipated her life expectancy would be shortened only by 10-20 years based on the potential problems and her dependency on others. She therefore, would need long provision of supportive services including supportive therapies, caretakers, assistive devices and medical providers from various specialties. She would benefit from increased intervention for spasticity, probably first by increasing Baclofen doses or adjusting her therapy regimen, considering other options such as Zanaflex, treatments such as Botox injections and especially Baclofen pump. She felt Veronica was a very good candidate for Baclofen pump and that it would probably help significantly with her diffuse spasticity with minimal cognitive side effects compared to the systemic medication options. Evaluation with Dr. Jaffa to help with comparison of her examination now versus one year ago and comparison of her skills off seizure medication versus on seizure medication would be helpful as her parents described that she seemed definitely more alert, communicative and interactive.

Records Reviewed:

Cyra, Emily M.D.: 10/4/02

ADDENDUM: 8/12/03

DAY IN THE LIFE VIDEOTAPE: UNDATED

Veronica awakens daily between 6:30 and 7:00 AM. Once out of her crib, mother performs sensory integration exercises, which include massaging gums with surgical brush and swiping upper mouth with Nuk brush. Following that, she performs what is called knocking of bones to all extremities. Stretching, sit ups and neck exercises are also performed. Cochlear Implant is then applied.

Mother then places Veronica in wheelchair and feeds her breakfast. Baclofen is administered in bottle. She then proceeds to don Veronica's orthotics which include bilateral AFO's and wrist splints. Veronica is then carried to the car for transport to school.

Veronica attends Avalanche Developmental Group five days per week from 8:30 - 2:30. She receives PT and OT at the center. Therapist first works on feeding skills. Veronica

remains with a right gaze preference. She has improved with bringing head to midline when feeding and understands request to do so. She requires assistance to hold a spoon in right hand. She does try to bring right hand to mouth to feed but is limited by tightness. She is observed reaching and grasping objects with right hand and can release objects.

Therapists describe Veronica as very alert to her environment. She is interested in what her peers are doing and is vocalizing more. At the end of the day, Veronica while being held by mother, attempts to wave bye to teachers by lifting right arm.

Veronica also received auditory/verbal therapy once per week for one hour in classroom type setting in Charlotte. Therapist works with Veronica and her mother to establish communication by vocalization. Veronica is observed grasping and holding a rattle and lightly shaking it with right hand. They also do book reading therapy in which Veronica is asked to vocalize when she wants therapist to turn page in book. A stop and go type game is also played. In this game, mother holds Veronica and therapist is on side. They proceed to walk down the hall and stop at random. Veronica is then asked to vocalize to resume walking. She does vocalize though response is delayed.

Veronica also receives educational services for the visually impaired in the home. Video depicts therapist with lighted strand of butterflies in her hand. The switch to activate the lights is on wheelchair tray. Veronica is asked to hit switch to make butterflies light, which she does twice. Book reading is also incorporated into session.

At the end of the day, Veronica's father arrives home and she smiles brightly. He then picks her up and plays with her by swinging and twirling her, which Veronica appears to really enjoy. Her father bathes her every night, plays with her again after the bath and puts her to bed for the evening.

Video then shows mother picking Veronica up out of her crib 2 days status post multiple lumbar punctures on 6/4/03. Veronica is visibly upset and cries loudly. Her entire body is stiff and she is inconsolable.

Records Reviewed:

A Day in the Life of Veronica Roman: Undated

ADDENDUM: 5/17/05

NORTH CAROLINA HOSPITAL: 8/29/03 - 8/31/03; 9/1/03 - 9/3/03; 9/24/03 - 10/2/03; 10/10/03 - 10/19/03; 10/25/03 - 11/1/03; 3/6/04; 3/7/04

North Carolina Hospital: 8/29/03 - 8/31/03
Admitted for placement of Baclofen pump. Intrathecal catheter was inserted up to the T5-T6 level and an umbilicus release was performed to release enough space in the superficial pocket. The pump was programmed to give a single bolus dose of 25 mcg and then subsequently was set at a daily rate of 75 mcg. Veronica tolerated the procedure well and was discharged to home on second day post surgery. Discharge instructions included continuation of oral dose of Baclofen and follow up visits with pediatrician and Dr. Andrews.

North Carolina Hospital: 9/1/03 - 9/3/03
Veronica was presented to the ER with complaint of irritability. Her parents reported uncontrollable fits and were also concerned about constipation. She was admitted for observation. A non-narcotic pain control pain medication regime was initiated. She was given appropriate bowel care and within 24, constipation had resolved. No further episodic fits were displayed and she was discharged home. It was noted that her extremities were markedly looser than they were when she arrived for Baclofen pump placement five days earlier.

North Carolina Hospital: 9/24/03 - 10/2/03
Veronica was admitted for evaluation secondary to altered mental status and possible seizure activity. She also had increased spasticity on admission. Parents reported Veronica had a decrease in loss of consciousness on the morning of admission, was unresponsive and had drooling, limpness, gurgling and clenched jaw. She was seen in an outside emergency department and transferred to NCH without event.

Initially neurology service felt Veronica's symptoms of seizure were possibly secondary to Baclofen toxicity as she had had a pump placed three weeks earlier. The infusion was decreased at that time. However, radiographs later incidentally showed that the intrathecal portion of the pump was displaced. The catheter was replaced by neurology on 9/26/03. Veronica was then transferred out of pediatric ICU to the floor from gradual increase of the pump rate. A video EEG was performed for monitoring of seizure activity, but Veronica did not have any further episodes of seizure-like activity during her stay. However, she did continue to have episodes of agitation, during which she was inconsolable. Small doses of Ativan seemed to calm her and allowed her to sleep. She was evaluated by neurosurgery, which felt that the episodes were possibly due to Baclofen withdrawal and increased the rate of her Baclofen pump. On the two days prior to discharge, she had only minimal

episodes of agitation. Her spasticity also improved throughout her course. Plan was to discharge her at current rate of Baclofen pump and oral Baclofen of 15 mg, three times daily which would be tapered in the future.

Veronica was also started on Dilantin for seizure control. Post-operatively, she had episodes of desaturation so Dilantin was changed to Carbamazepine. She was discharged on Carbamazepine with plan to gradually taper that medication.

From a respiratory standpoint, Veronica had one episode of decreased breath sounds, abut had been stable on room air throughout her stay. Veronica had a negative urine culture on 9/24/03, but since she had history of UTI's and they caused her agitation in the past, it was thought that infection could be a cause of her agitation episodes. A urine analysis drawn on the day of discharge, showed trace leukocyte esterase and a few white blood cells and bacteria. Plan was to prescribe antibiotics post discharge if culture came back positive. Veronica was discharged to home.

North Carolina Hospital: 10/10/03 - 10/19/03
Veronica presented to ER with swollen abdomen and tender incision at the margins with erythema, S/P placement of Baclofen pump on 9/26/03. She was admitted to neurosurgery. Her white blood cell count was elevated and throat swab was negative for group A Streptococcus. She was started on Baclofen and Tegretal along with IV Cefazolin for wound infection. Repeat examination subsequently did not demonstrate any significant change and she was switched to IV Vancomycin. Attempts were made at placement of a PICC (peripherally inserted central catheter) but were unsuccessful. A left saphenous Broviac was placed instead on 10/15/03. During that procedure, pediatric neurosurgery also placed a proximal catheter and revised the abdominal wound.

The remainder of Veronica's hospital course was uneventful. The abdominal wound healed quite well and her spasticity seemed to be improving. She was subsequently discharged to home with home health nursing arranged for infusion and wound care.

North Carolina Hospital: 10/25/03 - 11/1/03
Veronica was admitted for multiple episodes of emesis since early that morning. Emesis was originally phlegm like then changed to coffee ground like flecks with occasional red tinges. Mother reported Baclofen pump dose was increased by 10% one day earlier but that that had been advanced in the past without ill effects. She was receiving home IV Vancomycin through a left saphenous broviac. Impression on admission was viral gastroenteritis, rule out shunt block. IV hydration was initiated.

Shunt tap was performed on 10/26/03 and 8 cm of water was obtained. Runoff was excellent distally with proximal occlusion. The cerebral spinal fluid was sent for gram stain and culture. Broviac catheter was removed on 10/30/03 due to mycrobacterium infection. Veronica was started on oral antibiotic regime. Her condition improved and she was discharged to home.

North Carolina Hospital: 3/6/04
Veronica presented for vomiting and increased posturing. Head CT and shunt series were unremarkable. Chest x-ray revealed no focal infiltrates. Blood work was within normal limits. Plan was to continue to monitor her blood, urine and cerebral spinal fluid (CSF) cultures. She was given dose of Ceftriaxone and discharged home with instructions to return on 3/7/04 for follow up.

North Carolina Hospital: 3/7/04
Veronica remained afebrile, alert, smiled and had not vomited. Parents reported she was back to normal. Blood, urine and CSF cultures were negative. Second dose of Ceftriaxone administered. Plan was to continue to monitor cultures. Discharged to home.

NORTH CAROLINA HOSPITAL CLINIC: 11/6/03 - 1/20/05

North Carolina Hospital Clinic: 11/6/03
(Naomi Andrews, M.D./Neurosurgery) Veronica was one-week S/P hospital discharge. She presented for wound and Baclofen pump pocket check. Mother reported posturing improved but the spasticity in her lower extremities was still fairly severe. There had been no change in the breakdown of the pocket. Examination revealed severe diaper rash for which a prescription for Nyacin was issued.

North Carolina Hospital Clinic: 3/22/04
(Dr. A.J. Nicholas) Since last visit, Veronica underwent Baclofen pump placement with postoperative complications including displacement of the catheter and then pump infection. She had followed with ophthalmology, which suggested discontinuing her eye patching. She still was not having significant tone change despite current dose of 770 mcg of Baclofen a day. She was receiving OT, PT and ST 2-4 times per week. She used facial expressions and cried to communicate. She rolled both ways. She was not able to transfer and required assistance standing. She was dependent in bed mobility, feedings, bathing, dressing and undressing and community mobility. Equipment included cochlear implants, intrathecal Baclofen pump, a bath chair, an adaptive stroller and solid ankle AFO's.

Diagnosis was dystonic tetraplegic cerebral palsy. Plan was to repeat liver function tests and send note to Dr. Andrews and Willis for them to discuss whether or not to continue to increase Baclofen pump daily or do testing to look into flow of medication out of pump. Pediasure supplementation and current diet continued.

North Carolina Hospital Clinic: 3/29/04
Cochlear implant mapping and evaluation. Family used oral mode of communication. Family stated that Veronica had been vocalizing more and responding to sound more often in the last 6 months.

North Carolina Hospital Clinic: 5/12/04
(Ophthalmology/Darren Wade, M.D.) Mother reported Veronica seemed to be fixing and following more and that her tracking improved. However, she still had a preference to the right side. Impression:

- Mild cortical visual impairment
- Strong right gaze preference
- History of bacterial meningitis
- Intermittent exotropia
- Intermittent left hypertropia and left inferior oblique over action
- Improved amblyopia OS

It was felt that Veronica would benefit from services from the Mecklenburg Pre-school Program.

North Carolina Hospital Clinic: 6/7/04
(Naomi Andrews, M.D./Neurosurgery) Veronica was S/P intrathecal Baclofen pump placement. She had prolonged hospital course with irritability, probably an upper viral respiratory tract infection and some oral Baclofen withdrawal. She recently went home and was doing well. She was requiring 58 mcg of Baclofen. There was great improvement in her spasticity in her LE's as well as improvement in her UE's. The arching and dystonic posturing had improved greatly. She presented for suture removal.

The Ashworth in her LE's was 2. There were 2-3 in the UE's. She appeared much more relaxed and calm. She could now actually have some volitional movement of her head.

North Carolina Hospital Clinic: 7/26/04
(A.J. Nicholas, M.D.) Since last visit, Veronica had been hospitalized for a Baclofen pump placement in 6/04. Since placement, parents noticed tone in the bilateral UE's but some improvement in the LE's. Mother's concerns involved UE tone, posturing and need for Botox injections. Assessment: Mixed spastic dystonic tetraplegia cerebral palsy. Possibility of using intrathecal Baclofen as adding on bolus

infusions at nighttime when stiff was discussed. Botox would be considered to bilateral triceps to help with extensor posturing. Veronica would possibly benefit from having catheter raised higher up in the spinal canal, if possible.

North Carolina Hospital Clinic: 10/25/04
Veronica was seen for cochlear implant mapping.

North Carolina Hospital Clinic: 1/20/05
(Dennis Farmer, M.D.) Follow up for Cochlear implant. Veronica was having no active problems. She was continuing to try to use auditory verbal therapy and was making limited progress. Modifications to communication mode discussed. Plan was to discuss modifications at team meeting.

MECKLENBURG REGIONAL MEDICAL CENTER: 7/8/04 - 3/3/05
Veronica participated in PT 2X/week. Progress report covering period of 7/8/04 to 10/11/04 indicates Veronica underwent a catheter revision for her Baclofen pump secondary to scar tissue pushing it out of the spinal canal. Since her surgery, tone had fluctuated from extremely low to extremely high, but had been fairly stable over past 1-2 months. Her pump was set at 210 mcg daily and she also received a small dosage of oral Baclofen in the evening. Veronica's family has a pediatric Lite Gait unit for home use for six weeks. She was using it one hour daily. Treatment focused on ROM, postural control, transitions, partial weight bearing gait training and home exercise programming.

Veronica's overall tolerance of therapy had improved tremendously over the past three months. Though she protested occasionally when activities were difficult, she tolerated upright positions better with less hyperextension of her head and trunk. She was able to stick with a task for longer periods and was putting more effort into completing a requested task.

Veronica had slowly begun to regain her ability to roll independently. She was now able to roll from prone to supine independently over either side though it took extra time and verbal cues to move completely onto her back. She was rolling 1/2 to 3/4 of the way from supine to prone independently. She tolerated the prone position better with less cervical hyperextension. She could maintain elbows in flexion to weight bear on forearms, and was now successfully reaching for toys with her right hand in that position.

Though Veronica predominantly preferred to hyperextend her neck in the sitting position, she had become much more consistent with following directions to move her head into a neutral or flexed position and maintain it there for 5-10

seconds. She was able to maintain elbow extension for propping on one arm in sidesit. She could maintain her balance for 3-4 seconds before requiring minimal assistance. She was able to bench sit for at least 30 seconds with moderate support before pushing into standing through mass extension. When asked to return to sitting, she was able to flex at hips and knees with minimal assistance - 50% of the time.

Though Veronica was more successful with stepping prior to surgery, she had now begun to try taking steps again while supported in Lite Gait. She had taken one full step with the left foot and had taken several 1/2 steps with both feet, bringing her leg from an extended position to even with the opposite leg. Last week her mother reported Veronica has started kicking her legs again while in supine, which she had not been able to do since the catheter revision. She had good potential to begin taking consistent steps in the next month.

Despite increases in her Baclofen pump level, Veronica continued to demonstrate significant extensor tone in her UE's, LE's and trunk. Most significant was the tone in her UE's, which was difficult to break on the left, making dressing and bathing difficult for the family, and decreasing her ability to prop on UE's in sitting without risking injury to her wrists. Secondary to poor head control and tendency to hyperextend her neck, it was difficult for Veronica to focus and participate in activities that were in front of her. Hyperextension over her head also caused a displacement of her center of gravity resulting in loss of balance in sitting. Overall, her sitting balance had decreased since her surgery and was slowly returning. Veronica was nearing pre-surgical functional status and would continue to need direct PT intervention twice weekly to work on flexibility, strength, postural control, gait training and transitions, as well as recommendations for home exercise programming.

Last PT note dated 3/3/05 indicates Veronica was tolerating quad position well with little lateral support at hips. She did well with head in sitting when therapist sat behind her. Hand splints were fitting a little better with additional moleskin.

Records Reviewed:

Mecklenburg Regional Medical Center: 7/8/04 - 3/3/05
North Carolina Hospital: 8/29/03 - 8/31/03; 9/1/03 - 9/3/03; 9/24/03 - 10/2/03; 10/10/03 - 10/19/03; 10/25/03 - 11/1/03; 3/6/04; 3/7/04
North Carolina Hospital Clinic: 11/6/03 - 1/20/05

ADDENDUM: 2/14/06

MECKLENBURG REGIONAL MEDICAL CENTER: Outpatient: 9/27/00 - 6/28/01; 1/3/01 - 6/24/04 Emergency Room: 4/23/02; 9/24/03

Mecklenburg Regional Medical Center: 9/27/00 - 6/28/01
Veronica participated in outpatient OT. She was initially on schedule of 2X/week, which was then changed to a weekly visit at the clinic and twice a month at home. Due to her high level of distress during the last month or so of treatment, therapist decided to place Veronica on hold and look into the possibility of having the therapist at the ADG (Avalanche Developmental Group) go into the home. It was recommended that OT services be continued either individually or on a consultative model, depending on her level of tolerance and all the other services that were now being provided.

Mecklenburg Regional Medical Center: 1/3/01 - 6/24/04
Veronica participated in PT 1-2X/weekly. Last progress report dated 4/21/04 indicates that her functional skills continued to be extremely limited by her hypertonicity and muscular incoordination. She was demonstrating improvement in active flexion at multiple joints, but was yet unable to use them for intentional movements such as rolling or assisting with supine to sit. Her extensor tone interfered with her ability to be in a variety of sitting positions to engage in a play activity. Similarly, though Veronica was able to use her tone for stepping in the harness, she was only able to do so for a few steps, then was unable to break her LE extensor tone to continue. Hopefully, with continued management of her intrathecal Baclofen pump, her tonicity would decrease and allow her to better utilize the intentional movements that she was now demonstrating to progress further towards set goals. It was recommended she continue to receive outpatient PT 2X/week to address decreased flexibility, muscle incoordination and decreased functional mobility.

Mecklenburg Regional Medical Center: 4/23/02
Presented to ER for complaint of fever one day S/P shunt revision. Veronica was transferred to North Carolina Hospital for evaluation by Dr. Haines for possible infection.

Mecklenburg Regional Medical Center: 9/24/03
Presented to ER with complaint of altered mental status. History indicates Veronica was found by parents unresponsive in the morning. Upon arrival, Veronica had eyes open but did not respond to painful stimuli. Head CT showed increase in size of ventricles and Veronica was transferred to North Carolina Hospital. At time of transfer, mental status was somewhat improved and she responded to mother's voice, was moving her legs and was crying.

AVALANCHE DEVELOPMENTAL GROUP: 9/28/00 - 4/15/04

Avalanche Developmental Group: 10/10/02
Educational Evaluation. Vernica was 2.5 years old. She was enrolled in Avalanche Developmental Group (ADg) and received CAPMR-DD service, early intervention services with Sarah Randley with Mecklenburg Preschool Program, and early intervention services with Central NC for the Deaf and Hard of Hearing. She received PT, OT and ST from Avalanche. A cochlear implant was placed on 5/21/02.

Assessment instruments included the Developmental Observation Checklist System and Rossetti Infant-Toddler Language Scale. On the Developmental Observation Checklist System, her overall developmental quotient was a standard score of 64, placing her in the <1 percentile for children her age, a rating described as ''very poor.'' Scores were as follows:

	Raw Score	**%**	**Standard Score**	**Age Equiv**.
Cognition	31	<1	64	6 Months
Language	19	<1	64	7 Months
Social	23	<1	64	7 Months
Motor	15	<1	64	6 Months
Overall	45	<1	64	7 Months

Veronica's skills on the Rossetti Infant-Toddler Language Scale were as follows:

	Basal	**Ceiling**
Interaction-Attachment	3-6 Months	15-18 Months
Pragmatics	9-12 Months	15-18 Months
Gesture	No basal	12-15 Months
Play	6-9 Months	12-15 Months
Language Comprehension	0-3 Months	15-18 Months
Language Expression	3-6 Months	12-15 Months

Veronica was a 2 1/2 year old who had made significant progress in language development although her language skills remained significantly delayed. Her parents were pleased with her placement at ADG. Parents were encouraged to continue providing Veronica with a language rich

environment and to continue Auditory Verbal therapy to promote and monitor her speech and language acquisition.

Avalanche Developmental Group: 3/14/03
Developmental evaluation to assist with educational planning. By mother's report, Veronica's vision was recently tested and was found to be 20/60. She had intermittent exotropia and a preference for gazing to her right. She had been receiving services through the School for the Blind. She had hearing loss but had cochlear implant and now responded to music and spoken voice. She had been receiving therapy through North Carolina's program for young children with hearing problems. She had also been receiving OT and PT through Avalanche Developmental Group. Her parents obtained supplemental PT and ST. She attended a classroom at the Developmental Center 5 days/week and was also enrolled in the CAP-MR/DD program.

Cognitive skills were evaluated using face to face observation, observation of a videotaped therapy session with Veronica and task administration. Items from Bayley Scales of Infant Development-Second Edition were attempted. Veronica had significant visual, auditory and motor impairments that impacted her ability to respond to testing. A developmental equivalency was not established. Her MDI (overall standard score) was clearly below 50.

Veronica's highest pass occurred at the 6-month level on the Bayley II. She responded playfully to and smiled at her mirror image. She displayed awareness of new surroundings and new people. She vocalized differently to reflect different attitudes and emotions. She displayed frequent episodes of extensor tone. She required external support for positioning that enabled her to reach. She had limited head control and showed a strong right gaze preference. She exhibited difficulty in shifting gaze between objects placed in her line of vision. She smiled, cried or stopped moving when in novel situations around people that she did not know. Veronica did not imitate verbally or non-verbally. She demonstrated emerging understanding of cause-effect relationships.

The Interview Edition of the Vineland Adaptive Behavior Scales was administered in order to obtain additional information about her skills. The respondent was her mother. Results were as follows:

Domain	**Standard Score**	**Age Equivalent**
Communication	57	11 mos.
Daily Living Skills	55	12 mos.
Socialization Skills	61	12 mos.
Motor Skills	38	2 mos.
Adaptive Behavior Composite	49	10 mos.

Communication: Veronica did not use words however she had begun to shake her head ''no.'' She demonstrated understanding of at least 10 words. She consistently turned toward sounds. Her vocalizing and social awareness had both increased as a result of auditory -verbal therapy.

Daily Living Skills: Veronica's motor limitations impacted her ability to perform many activities of daily living. However, she was eating solid foods without choking. She accepted liquids through sippy cup. She indicated when hungry. She was tolerating a greater variety of stimulation but could at times be over-stimulated by noise.

Socialization Skills: Veronica was described as social. She showed interest in others' activities. She showed anticipation of being picked up. She laughed or smiled in response to positive statements from others. She waved bye-bye on request. Social skills were relative strength.

Motor Skills: Veronica continued to require sitting assistance to perform most fine motor tasks. She had frequent episodes of extensor tone.

In summary, it was difficult to establish a precise estimate of Veronica's cognitive function due to her multiple impairments including visual problems, a history of hearing loss, hypertonicity and severe language delays. Since last evaluation, she had shown progress in her ability to tolerate novelty as well as increased social awareness and responsiveness. During the evaluation, she demonstrated the ability to access roll and flat surface switches. Her understanding of cause and effect using voice input devices was still emerging. She would benefit from suggested modifications for interacting with assistive technologies as described below. Her language rich home and classroom environments were providing stimulation that was beneficial to her communication and overall development.

Recommendations:

- Mecklenburg County Schools' Preschool Individualized Education Program review results of evaluation to determine the most appropriate education services for Veronica.
- Veronica should continue enrollment in the CAP-MR/DD Program
- Continuation of speech-language therapy
- Continuation of PT including supplemental therapy
- Continued OT
- Oral-motor skills evaluation
- Classroom with low pupil to teacher ratio.
- Computer strategies

- Use of items on switches to make them more tactile
- Encourage access and understanding of use of Touch Window
- Use of switches for communication and learning at home, in classroom and in community
- Voice input device with levels, such as Step-By-Step with Levels Communicator
- Use of communication bracelet to encourage others to initiate conversation with Veronica
- Use of communication notebook to share what happened at school or home
- Additional devices to be introduced as Veronica becomes more skillful with her use and understanding of voice output devices to encourage choice making and communication in short phrases
- Adapted computer peripherals and software to enhance Veronica's cognitive skills
- Assistive devices and computer that includes:
  - A switch-latch timer
  - Step-By-Step Communicator with Levels or similar switch
  - Switch Interface for a PC
  - Big Switch or similar switch
  - A Jelly Bean or similar switch
  - Software such as: Songs I Sing at Preschool, Eensy & Friends, Humpty & Friends and Talk Time with Tucker

Avalanche Developmental Group: 416/03 - 4/15/04
Veronica's IEP indicates she is in pre-school. She is described as friendly, very social, enjoys contact with people and is interested in learning. She participates in all activities at her child care. She receives special education services 5 days a week, OT, PT and ST 2X/week for 30 minutes.

PT reported Veronica was able to roll to either side and to tummy but movement is not smooth and was in extensor pattern. She needed assistance to move to all fours. She was able to move from sit to stand with support. She was able to lift her head in supported all fours. She was able to sit with support and was able to maintain her head in upright position for short periods but she pushed back into extension with her head falling back into extension. She could lift her head forward with great effort.

Communicatively, she is very social. She expressed herself through vocalization, smiling and laughing. She turned her head toward environmental sounds and vocalizations. She enjoyed music and finger plays.

Cognitively, she was able to demonstrate an understanding of cause/effect relationships. She had increased vocalizations

and social awareness recently. She was beginning to express her wants and needs through a combination of gestures and vocalizations.

Veronica reached and grasped with her right hand more than her left. She was learning to reach at specific locations for objects and is beginning to release in specific locations. She tended to keep her head turned to right side but could bring it to midline. She most often used one hand on an object but could place both hands. She pressed adaptive switch _____ and _____ _____ to grasp and take a filled spoon to her mouth.

Veronica became upset at times and had some difficulty calming, but has shown much improvement. She needed a sensory approach as well as means to communicate her needs.

KANDOO CLINIC: 1/8/02 - 11/14/05
Pediatric treatment for typical childhood illnesses and immunizations. Illnesses included bronchitis, otitis media, viral URI, gastroenteritis, pharyngitis, viral rashes, bronchitis.
Visit of 6/28/05 indicates Veronica was on Miralax and Baclofen. Weight was 40 pounds, 13 ounces. She had cochlear implant in left ear and Baclofen pump. She was scheduled to go to William's Elementary School. She was getting ST 3X/week, PT and OT twice a week. She saw a pediatric neurologist every 3 weeks and an ENT once yearly.

NORTH CAROLINA HOSPITAL: 11/17/00; 12/15/00 - 12/19/00; 12/22/00; 1/9/02 - 1/10/02; 4/21/02 - 4/22/02; 4/23/02 - 4/24/02; 5/21/02 - 5/22/02

North Carolina Hospital: 11/17/00
Veronica presented for shunt tap. Tap was performed and revealed fluid collection in occiput. Veronica was asymptomatic. Mother was advised to follow up with neurosurgeon in one week.

North Carolina Hospital: 12/15/00 - 12/19/00
Veronica was admitted for shunt revision, peritoneal flap for cerebrospinal fluid leak. She tolerated the procedure well and was transferred to the floor in stable condition. In the immediate post-operative period, she was very agitated and pain control was readily pursued. However, she continued to be agitated despite frequent dosing of Morphine and Versed. It was felt her increased agitation could lead to flap closure failure and she was transferred to pediatric ICU for more aggressive sedation. A nasal duodenal tube was placed for nutrition, as she was on nothing by mouth status. The agitation decreased and she was transferred back to the floor on 12/17/00. She improved and duodenal tube was removed on 12/19/00. Veronica was discharged to home.

North Carolina Hospital: 12/22/00
Veronica presented with complaint of vomiting. Work-up to rule out shunt infection was negative. Diagnosis: UTI vs. gastroenteritis.

North Carolina Hospital: 1/9/02 - 1/10/02
Veronica was admitted for emergency shunt revision due to proximal shunt revision. Following surgery, she did well overnight and was discharged home the following day.

North Carolina Hospital: 4/21/02 - 4/22/02
Veronica presented to ER with increased irritability and decreased activity without obvious signs of illness. Shunt malfunction was suspected and CT revealed large collection of fluid around the shunt assembly on the scalp. A shunt tap was performed but revealed inconclusive results so decision was made to proceed with exploration of the shunt. Her ventricular catheter was found to be fractured. The distal emptying pressure was elevated through her valve and low through the distal catheter. As a result, her proximal shunt and valve were replaced. Postoperatively, she demonstrated an intact shunt in good position and she was discharged to home.

North Carolina Hospital: 4/23/02 - 4/24/02
Veronica developed fever of 102 degrees while at home. She was transferred to NCH from local hospital where she was found to have erythema tracking down the thoracic portion of her shunt. Once at NCH, she was started on antibiotics. Her shunt was tapped and found to be functional. Blood and cerebral spinal fluid cultures were negative. She was discharged to home on hospital day #1 to complete seven-day course of antibiotics.

North Carolina Hospital: 5/21/02 - 5/22/02
Veronica underwent left cochlear implantation using facial nerve monitoring and operating microscope. She was discharged home the following day.

NORTH CAROLINA HEALTH CARE: 2/8/01 - 2/15/02

North Carolina Health Care: 2/8/01
(Rodger Jaffa M.D.) Parents questioned the need for ongoing muscle relaxation medication. Veronica was on Valium for irritability, which was much better. She slept well. Feeding was going well. She had bilateral hearing aides placed and seemed to be improving with auditory responsiveness. She was using her vision to track. She had more alert periods and could be laid down and left alone for periods of time and did not have to be constantly held. She had no seizures.

Examination revealed poor head control. Eyes were not always conjugant and she often had an exotropia. Tone was still fairly increased but appeared manageable on current medication regimen. Recommendations included no change in anti-spasticity medications. Seizure medication would also remain the same and would be re-addressed at next visit.

North Carolina Health Care: 3/5/01
(Darren Wade, M.D.) Veronica had cortical visual impairment. Mother reported she seemed to track objects at home. She was receiving services from the Mecklenburg Preschool program. On examination, Veronica fixed and followed with both eyes. Impression:

- Mild cortical visual impairment
- Intermittent exotropia
- Strong right gaze preference
- History of bacterial meningitis

Veronica would continue to benefit from services from the Mecklenburg Preschool Program.

North Carolina Health Care: 3/23/01
(A.J. Nicholas, M.D.) Since last visit, Veronica had shunt revision. She had been diagnosed with hearing impairment. She had intermittent fix and follow. She had 4+ head lag on pull to sit. She was not rolling over or sitting up independently. Impression: Spastic tetraplegic cerebral palsy S/P meningitis. Plan was to wean off Valium and increase Baclofen. Foods and textures were to be advanced as well.

North Carolina Health Care: 4/30/01
(Jackie Kennedy, M.D.) Veronica had CT of temporal bone. Mother reported that she had some problems with irritability when they put hearing aides in. Veronica appeared to be responding some to the hearing aides. Assessment: Ongoing ossification of the cochlear secondary to meningitis. If Veronica was to be considered for cochlear implant, it would have to be soon. The right cochlear was no longer patent and an implant could not be placed in that ear. The left was likely not patent also although with some difficulty a split array could be used. Parents were not prepared to have Veronica undergo a relative long surgery at that point in time.

North Carolina Health Care: 8/13/01
(Roger Jaffa M.D.) Neurology follow up. Veronica remained seizure free on medication. She was making good progress at Avalanche Developmental Group. Mother had questions re: cochlear implant and why Veronica had fluctuations in her mood. It was reasonable to consider tapering off medications.

North Carolina Health Care: 8/28/01
(A.J. Nicholas, M.D.) Veronica returned with continued poor tolerance in the sitting positions and increased posturing of LE's. She was in OT 2X/week, PT 3X/week and ST 1X/week. Table foods were advanced to Stage 3 baby foods. She continued with intermittent fix and follow with occasional babbling sounds. Tone was 2+ Ashworth in all extremities, left greater than right.

Baclofen dosage adjusted to reduce spasticity. Issue of cochlear implants could be addressed by ENT. Pepcid was continued for reflux disease.

North Carolina Health Care: 1/22/02
(Anthony Marietta, M.D.) Mother reported Veronica was doing well S/P shunt revision.

North Carolina Health Care: 1/29/02
(Richard Luz, M.D.) Veronica was S/P shunt revision. Parents were concerned about her apparent sensitivity to placement of left-sided hearing aid and believed she had irritation of ear canal. Otherwise, she was improving with better appetite and better head control since last visit.

Veronica could make two syllable sounds but no distinct words. She could sit with support for approximately one minute. She had fair head control. She was able to move her LE's as well as her UE's, although her right UE greater than her left UE. Veronica was able to attempt to feed herself using her RUE. She could remove her socks. She could track past midline and would turn her head towards sound with and without use of hearing aids.

Reglan and Baclofen were increased. Parents were instructed to increase Veronica's caloric intake. Recommendation was that they avoid hearing aide use over next few days in left ear and allow it to heal.

University of North Carolina Health Care: 2/15/02
(Dennis Farmer, M.D.) ENT consultation. Parent's reported Veronica did respond to some sounds although no spoken language. She did make some babbling sounds. Examination revealed some wax in the left ear. Remainder of examination was normal.

Discussion held regarding cochlear implants. It was felt Veronica was implant candidate following further auditory, verbal and audiological evaluation. CT would be repeated to determine extent of cochlear ossification. She would need a split electrode array, compressed electrode array and regular electrode array and Med El device was discussed.

PEEDS SPEECH: 8/21/02

Speech and Language Summary. Veronica was S/P cochlear implant. Since the implant surgery, she had made several gains that allowed her to pass sections of the evaluation that she would not have passed before her surgery. She showed a differing response to mom and dad's voices, she moved in response to voice and now vocalized to caregivers smile and talk. She vocalized two different sounds. Veronica's language level appeared to be similar to that of a 3 month-old infant. Her highest scores were found in the interaction-attachment section where she demonstrated different responses to family members, smiles while playing alone and became livelier with familiar people. She also seemed to show sensitivity to other's moods.

Veronica was able to move her head from side to side but was unable to hold her head up without support. She had very limited ability to move her arms and legs, often elevating her trunk to turn herself around while lying on the ground. In the last few weeks, she had begun to use her right arm to reach for objects. Her ability to maintain eye contact was limited. She had just begun to make eye contact during feeding and diminish crying with adult eye contact (brief). The following recommendations were made:

- Continued aggressive audiological management
- Continue all therapies
- Consider a sensory integration evaluation
- Begin speech and language therapy once a week with an emphasis on development of audition
- Consider exposure to sign language.

THE SCHOOL FOR THE BLIND: 4/4/01 - 2/14/03

The School for the Blind: 2/14/03
Functional Vision Evaluation. Veronica had made much progress in the past year with more consistent visual responses. She had been more alert, responsive and much easier to calm and to engage in play. She continued to respond best visually if there were clear, uncluttered pictures, black and white pictures, bright, high contrast toys and presentation was slow and expectations were clear. Veronica's physical tone kept her head turned to one side most of the time and some days she was able to turn her head back to midline and track visually. Other days, she had difficulty overcoming her strong physical challenges.

Veronica had functioned extremely well in a classroom with same age peers with and without disabilities. She enjoyed group times and individual sessions with her teachers most of the time. Recommendations:

- Teachers and therapist read fact sheet on Neurological Visual Impairment and utilize suggestions in their activities and presentation with Veronica

- Functional vision assessment be ongoing process
- Therapist/teachers understand that positioning is of utmost importance for Veronica
- Teachers/therapist know that Veronica enjoys books and will reach out and feel textures willingly.
- A multi-sensory approach to learning be used with Veronica
- Continue to encourage Veronica to ''look and see'' and praise her attempts to focus on objects
- Continue to be followed by her pediatric ophthalmologist

WYATT, JAZMINE M.S., CCC-SLP: 1/1/03; 5/11/03

Wyatt, Jazmine M.S., CCC-SLP: 1/1/03
Veronica was attending weekly parent participation speech and language therapy sessions with her mother. She was working on increasing her comprehension of auditory signals and language as well as increasing her use of speech/language through vocalizations. She alerted to loud and medium environmental and speech sounds at close range (2-4 feet), 60% of the time. She alerted to her name about 40% of the time but she did not yet search for the speaker. She focused her eyes on the ''Learning to Listen: sound association object and requested more auditory input by vocalizing or reaching out her arm about 50% of the time. She continued to increase her vocalizations when given prompts or input through vocal play or turn-taking parentese. She requested ''more'' (vocalizing with intent) for a variety of activities 5 out of 10 times. She was starting to imitate bye-bye and pat-a-cake motions when given hand over hand support. She continued to use mainly central vowels in her vocalizations.

Wyatt, Jazmine M.S., CCC-SLP: 5/11/03
Veronica had shown improvement in her ability to alert to environmental sounds and her name. She alerted to medium environmental speech sounds at about 6 feet, 65% of the time and to soft sounds at close range (2-4) feet, 50% of the time. She alerted to her name about 50% of the time (an increase from 40% in January), and she had started to search for the speaker by slow movements (such as head turn) with a delay. She focused her eyes on the ''Learning to Listen'' sound association object for an average of 1-2 seconds with auditory input and prompts to ''look at'' the toy. She requested more auditory input by vocalizing or reaching out her arm about 60% of the time (also with prompts). She did not yet choose between Learning to Listen sound association objects but that behavior was currently being modeled for her. Veronica continued to increase her vocalizations when given prompts or input through vocal play or turn-taking parentese. She also worked on vocalizing to express ''open, blow, up and go.'' She sometimes imitated an open/close

hand motion to accompany a familiar song. She continued to use mainly central vowels in her vocalization. Additional vowels were modeled and input on a rotating basis.

LYON MEDICAL CENTER: 8/14/03; 5/6/04; 6/2/04 - 6/12/04

Lyon Medical Center: 8/14/03
Veronica underwent trial of intrathecal Baclofen prior to consideration of placement of Baclofen pump. No adverse responses were observed and she was discharged to home.

Lyon Medical Center: 5/6/04
Veronica underwent CT/Myelogram to evaluate Baclofen pump as she had little change in spasticity following placement. Pump was found to be extra-dural. Results were discussed with Dr. O'Riley and Veronica was discharged to home.

Lyon Medical Center: 6/2/04 - 6/12/04
Admitted for Baclofen pump revision. History indicates pump never functioned to a satisfactory level and it was ultimately determined that the catheter had ineffective placement. Lumbar laminectomy for direct placement of Baclofen pump was performed. Veronica had much more satisfactory results in terms of relief of her spasticity afterwards and was able to go down from dose of 900 mcg to 60 mcg/day.

Almost immediately postoperatively, Veronica developed fever and then later extreme irritability and poor feeding. Cultures of blood and urine were negative. Chest x-ray revealed mild infiltrate, which was treated with seven days of antibiotics. She was later found to have ulcerations and petechiae in the soft palate and posterior pharynx, which was felt to be probably due to a concurrent viral infections at time of surgery. She gradually improved with supportive care and IV hydration. By time of discharge, she was using some viscous Lidocaine to aid with pain during eating, but overall, was doing well with adequate oral intake off IV fluids. Fever also resolved and she was discharged to home.

WILLIS, WESLEY M.D.: 2/3/04 - 9/1/05
Veronica presented on numerous occasions for Baclofen pump emptying, refilling and re-programming.

Willis, Wesley, M.D.: 2/27/04
Since last programming, there was no change in Veronica's spasticity. Examination revealed marked increased muscle tone with rigidity in the legs and spasticity in the arms. He was able to reduce every muscle group into neutral position, the arms easier than the legs. Veronica cried for no apparent reason. She had decreased vision, reactive pupils, roving eye movements. Motor exam showed quadriparesis with rigidity.

Willis, Wesley, M.D.: 2/27/04
Baclofen increased to 60 mcg.

Willis, Wesley, M.D.: 3/9/04
Veronica had not benefited from increase in Baclofen. Medication increased.

Willis, Wesley, M.D.: 4/20/04
Mother reported that physical therapist's believed Veronica was becoming somewhat less stiff. She was scheduled for myelogram to determine whether intrathecal catheter was fully communicating with the lumbar subarachnoid space.

Willis, Wesley, M.D.: 6/28/04
Veronica was S/P re-implantation of Baclofen pump catheter. She was seen on 6/17/04 by Dr. Andrews who noted improvement in spasticity in her LE's and some improvement in her uppers as well as decreased arching and dystonic posturing. At that time, she had Ashworth of two in her LE's and two to three in her UE's and appeared relaxed and calm. She had some volitional movement of her head. Volitional movement was noted in right hand.

On examination, Veronica had Ashworth of 3 in the UE's and 2-3 in the LE's. Spasticity seemed to be somewhat greater. He attributed that to decreasing the oral Baclofen although he did not know if a connection definitely existed. For the time being, plan was to taper and discontinue Baclofen (oral). Intrathecal Baclofen would remain the same.

Willis, Wesley, M.D.: 7/9/04
Veronica's catheter now resided in the upper lumbar region. In general, she had been better, but that led them to try to decrease her oral Baclofen. With decrease in Baclofen there was noticeable increase in spasticity. She had Ashworth of 3 in the UE's and 4 in the LE's. Intrathecal Baclofen was increased and oral medication continued to be tapered.

Willis, Wesley, M.D.: 8/3/04
Veronica was seen by Dr. Nicholas who suggested using intrathecal Baclofen with bolus effusions at nighttime when she was stiff and was considering Botox to bilateral triceps in order to help with extensor posturing. He also suggested raising the catheter to higher position in the spinal canal if possible and discontinuing Pediasure supplementation while watching her weight. Intrathecal pump adjusted.

Willis, Wesley, M.D.: 9/16/04
Mother reported Veronica was doing no better with increase in Baclofen but it was very clear on examination that she was more mobile than she had been, particularly with the RUE. Veronica was able to move her legs and arms although it was very clear that as soon as one started to evaluate her, she locked into a decerebrate posture with arms and

legs extended and back arched. On examination, Veronica was able to grasp her hand on a toy and actually push on the spinning portion of the toy to make it move. She fixed her eyes clearly on it. He felt there was definite effect on the tone, more so in the UE's. Baclofen dosage continued.

Willis, Wesley, M.D.: 11/10/04
Veronica had a clasp knife tone once rigidity was overcome. She had tight heel cords. She did not have any fixed contractures. Hands were open. She was able to sling a toy. She often went into opisthotonic posture. Pump refilled and reprogrammed.

Willis, Wesley, M.D.: 12/25/04
Mobility improved somewhat since last visit. Therapists were noticing increased mobility and decreased spasticity. He observed volitional movement of Veronica's right arm greater than left. She was able to bring objects up to her mouth without difficulty. Pump refilled/reprogrammed.

Willis, Wesley, M.D.: 3/24/05
Veronica's tone was diminished in comparison with where it had been in the past. The legs actually showed fairly nice tone. Arms were still somewhat stiff and rigid as might be expected given location of the pump.

Willis, Wesley, M.D.: 4/7/05
Therapist noted that there seemed to be a swollen area next to the catheter on the left side of the back. Examination revealed mild prominence that was not fluctuant. There was no fluid. It felt like hypertrophied muscle. Area looked normal and nothing needed to be done.

Willis, Wesley, M.D.: 9/1/05
Spasticity remained prominent and unchanged. There were plans to have the pump evaluated for its integrity by Dr. Andrews. Pump was emptied, refilled and reprogrammed.

Records Reviewed:

Avalanche Developmental Group: 9/28/00 - 4/15/04
* IEP Dated 4/16/03 - 4/15/04 - In File
Mecklenburg Regional Medical Center: Outpatient: 9/27/00 - 6/28/01; 1/3/01 - 6/24/04 Emergency Room: 4/23/02; 9/24/03
The School for the Blind: 4/4/01 - 2/14/03
Willis, Wesley M.D.: 2/3/04 - 9/1/05
Kandoo Clinic: 1/8/02 - 11/14/05
Peeds Speech: 8/21/02
North Carolina Healthcare: 2/8/01 - 2/15/02
North Carolina Hospital: 11/17/00; 12/15/00 - 12/19/00; 12/22/00; 1/9/02 - 1/10/02; 4/21/02 - 4/22/02; 4/23/02 - 4/24/02; 5/21/02 - 5/22/02
Lyon Medical Center: 8/14/03; 5/6/04; 6/2/04 - 6/12/04
Wade, Darren M.A., CCC-SLP: 1/1/03; 5/11/03

ADDENDUM 3/6/06

WILLIS, WESLEY, M.D. 11/18/05
Veronica was seen in follow-up. Dr. Willis indicated that since the revision of her intrathecal pump, things have not been the same as the initial results. Her doses have had to be pushed up, making refills necessary every three weeks. She was on a bolus dose up to 50 mcg over a 5 minute period, four or more times a day. His plan was to continue to reprogram her pump to increase the number of doses. She was to continue Baclofen orally 1 mg per ml 5ccs three times per day. She would return 12/8/05 for emptying, reprogramming and refilling of her pump.

Record Reviewed:

Willis, Wesley, M.D.: 11/18/05

Activities Of Daily Living

Sleep Pattern

Arises: 6:00 a.m.
Retires: 6:00 -7:00 p.m.
Sleep Difficulties: None. She sleeps through the night. Update 2/17/06: Sleeps through the night.

Independence In

Dressing: Not functional. Update 2/17/06: All the Same
Housework: Not functional.
Cooking: Not functional.
Laundry: Not functional.
Yard Work: Not functional.

Social Activities

Organizations Pre/Post: Update 2/17/06: They meet with other couples who have little girls with similar needs so the children and parents can interact. This is done monthly.

Personal Habits

Smoking: No one smokes in the home.

Socioeconomic Status

Children: Only Veronica.
Number in Residence: 3 total.
Type of Residence: 2 story home, not accessible. 2/17/06: Same.

Income

Current Financial Situation: Update 4/29/03: Veronica is not receiving SSI but she is on Medicaid as her secondary insurance. Mary has not been able to resume working.
Update 2/17/06: None. Medicaid is now available. CAP MR/DD supplies diapers and underpads. They will pay for summer program at Avalanche from May through August, 8:30 a.m. to 2:30 p.m. They also pay for respite care.
Veronica is also covered by Health insurance.

Conclusions:

Careful consideration has been given to all of the medical, psychosocial, and rehabilitation/mental health counseling data contained within this file and my report. In addition to this data, consideration is given to the research literature on Cerebral palsy, Developmental delay and Cochlear implants, and attention is paid to the clinical practice guidelines for the treatment of these diagnoses promulgated by multiple sources and cited in the Life Care Plan. Correspondence with treating physicians was again issued and this updated life care plan was also reviewed by our consulting Physiatrist, Andrea Zotovas, M.D. All of these steps are taken to help in establishing the medical, case management, rehabilitation and psychological foundations for the Life Care Plan.

Veronica remains significantly disabled secondary to the development of streptococcus pneumococcal meningitis and the resulting complications. She is nonfunctional for independent living skills, and it is anticipated that she will remain very dependent throughout the remainder of her life.

The updated Life Care Plan outlines all of her needs dictated by the onset of disability throughout her life expectancy. In addition to the recommendations specifically for Veronica, education and counseling is provided to the family members in order to assist them in adjusting to her disability and becoming even better disability managers.
Veronica will require care and support for the remainder of her life expectancy. Home care assistance will provide the

least restrictive environment while providing the support, interaction, and structure Veronica requires. The updated life care plan will outline the cost of privately hiring caregivers, versus hiring caregivers through a home health agency. As a third option, for comparative purposes, facility care will be outlined post-age 21. Additionally, the Life Care Plan, attached as Appendix A, will outline all of Veronica's medical care, equipment needs, supplies, medications, therapy/habilitation recommendations and other considerations as outlined by her treating physicians and therapists.

The Vocational Worksheet prepared in 2002, was not updated as no changes were anticipated.

After you have had an opportunity to review this narrative report and the attached appendix, please do not hesitate to contact me should you have further questions.

Respectfully Submitted,

Paul M. Deutsch, Ph.D., C.R.C., C.C.M., C.L.C.P., F.I.A.L.C.P.
Licensed Mental Health Counselor
PAUL M. DEUTSCH & ASSOCIATES, P.A.

ATTACHMENTS: Appendix A - Life Care Plan - Update 2006