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Bilirubin Encephalopathy/Kernicterus and The Newborn Infant: Implications for Life Care Planning

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Abstract. *Bilirubin encephalopathy, also known as kernicterus, is caused by high bilirubin levels in early infancy and results in neurotoxicity that can lead to irreversible life-long brain damage. An increasing number of these cases are being identified in infants and children and some of these cases have been sources of litigation. This article will identify risk factors in infants with high bilirubin levels as well as discuss current practice guidelines noted by the American Academy of Pediatrics (AAP). Additionally, recommendations by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) will be discussed. Finally, implications for the life care planner in developing life care plans for children with kernicterus will be discussed.*

Introduction

Most full-term babies in the United States are born healthy and spend their neonatal period (the first 28 days of life) growing and developing. Some of these infants, approximately 50-60%, develop jaundice or hyperbilirubinemia in the first week of life (AAP News, 2004). Jaundice is a yellowish discoloration in skin pigment caused by too much bilirubin (a breakdown product from red blood cell destruction) in the blood, and hyperbilirubinemia in infancy may result from bilirubin (Wong, 2001). Hyperbilirubinemia leads to jaundice in the skin as well as the sclerae of the eyes and the nails and is commonly seen in newborns (Wong, 2001). In most cases, infant jaundice is benign and resolves on its own. However, in some cases, jaundice requires treatment with phototherapy and fluids, and, on occasion, with exchange blood transfusions. There are a few uncommon, but significant cases, in which an infant's bilirubin value can rise to high and dangerous levels. The rise can happen in a short period of time, and, if not treated appropriately and timely, may lead to a neurotoxicity resulting in irreversible brain damage known as bilirubinemia encephalopathy or kernicterus. For purposes of this article, the words jaundice and hyperbilirubinemia in infancy will be used interchangeably to describe the same condition. Likewise, the terms bilirubin encephalopathy and kernicterus will be used interchangeably to describe the same condition that results in neurotoxicity as these terms are both used in referenced literature.

History of Bilirubin Encephalopathy

"Kernicterus" is defined as a yellow staining of the nuclei of the brain, particularly in the brain's basal ganglia, cerebellum and hippocampus, that is diagnosed on autopsy (Merenstein

& Gardner, 2002). Although historically the terms "kernicterus" and "bilirubin encephalopathy" have been used interchangeably, the American Academy of Pediatrics has recently advised the appropriate terminology to be used (AAP, 2004). During the acute disease state, when manifestations of acute bilirubin toxicity are seen in the first few weeks after the infant's birth, the condition is termed "acute bilirubin encephalopathy." The term "kernicterus" is to be reserved for the chronic and permanent clinical sequelae of bilirubin toxicity (AAP, 2004).

Historically, "kernicterus" was seen as a complication of hemolytic diseases including erythroblastosis fetalis (O'Keefe, 2001; National Association of Neonatal Nurses position statement, 2003). Although kernicterus was prevalent in the 1950s and 1960s, in the late 1980s and early 1990s this disease was thought of as nearly non-existent as a result of maternal RhoGAM therapy, neonatal phototherapy and exchange transfusion intervention for infants with hyperbilirubinemia (O' Keefe, 2001; Springer, 2001). Springer (2004) notes that kernicterus virtually disappeared from the clinical scene, only to reappear during the mid to late 1990s. Some reports (O'Keefe, 2001)
indicate that it has re-appeared due to the following factors:

- increased desire for mothers to breastfeed which can lead to suboptimal intake for some babies.
- earlier discharge of newborns from the hospital, some as early as within 48 hours after birth.
- inadequate or not timely follow-up, especially follow-up for jaundice.

The incidence of bilirubin encephalopathy is not currently known as this disease is not reported to the Centers for Disease Control (CDC, 2001). At present; however, there is a known increase in reported cases with such entities as the Registry for Kernicterus at Pennsylvania Hospital in Philadelphia reporting 90 documented cases from 21 states from 1984 through 2001, the time span for which for which published data is available (CDC, 2001). Since 2001, additional cases have been identified (CDC, 2004).

The CDC is working with the pilot registry at Pennsylvania Hospital in Philadelphia, known as the BIND (Bilirubin Induced Neurologic Dysfunction) Center, to help track the cases. Case reporting started in 1984 and, as of September 2002, the BIND Center has reported 125 cases of confirmed kernicterus in healthy term or near term infants from 34 states. Additionally, the Robert Wood Johnson Medical School Kernicterus Research and Prevention Center along with The New Jersey Department of Health and Senior Services will develop and implement a system to monitor and track new cases (CDC, 2004). The New Jersey Center's preliminary research for infants born between 1992 and 2001 has identified 82 cases of kernicterus, with 7.5 cases per 100,000 live births (CDC, 2004).

Since the 1990s, the pediatric medical community has debated the need to identify and treat neonatal hyperbilirubinemia without hemolytic disease (Newman & Maisels, 2000). One question repeatedly asked is, "What level of bilirubin leads to bilirubin encephalopathy?" The answer to this question is not black and white and there is currently no evidence that a specific bilirubin level causes neurotoxicity. Furthermore, bilirubin levels are influenced by postnatal age, rate of rise, and presence of co-morbidities (Bhutani & Johnson, 2004). In addition, the actual overall risk for kernicterus is not really known and harmful bilirubin concentrations vary in different ethnic and geographic groups (AAP, 1994). In the Journal of Perinatology, Shapiro (2005) notes that, "The clinical expression of bilirubin-induced neurologic dysfunction (BIND) varies with the location, severity, and time of assessment, influenced by the

amount, duration and developmental age of exposure to excessive free bilirubin" (p. 54). Further, Shapiro (2005) reports, "Although total serum bilirubin (TSB) is important, kernicterus cannot be defined solely on TSB" (p. 54).

What is clear from the literature is that hyperbilirubinemia can cause irreversible neurotoxicity and that, with appropriate, aggressive treatment, it is known to almost always be preventable (AAP, 2004). Since 1994, the AAP has published several articles related to addressing kernicterus and bilirubin encephalopathy. The CDC has released publications and the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has listed kernicterus as a "sentinel event" (JCAHO, 2001). These actions have all been taken because kernicterus is thought to be largely preventable. The Parents of Infants and Children with Kernicterus (PICK), a grassroots organization formed to address these very issues and to work towards educating both healthcare professionals and lay people alike, has been very involved with all of these agencies.

In regard to risk, Kenner and Lott (2003) documented that there is a greater risk for bilirubin encephalopathy with higher elevated bilirubin levels. They noted a 50% higher risk for infants with serum bilirubin levels of 30 mg/dl or greater and a 10% higher risk for bilirubin levels of 20-25 mg/dl. Kenner and Lott (2003) further suggest that the prevention of elevated levels of free bilirubin is a principle method to eliminate kernicterus.

According to several sources, the following factors have been identified as risk factors for hyperbilirubinemia (AAP, 1994; Dennery, Seidman, & Stevenson, 2001; JCAHO, 2004):

- Jaundice appearing in the first 24 hours after birth.
- Inadequate nutrition and hydration as a result of suboptimal breastfeeding.
- Near term neonates 35-37 weeks gestation.
- Bruising and cephalohematomas (head bruising between skull bone and periosteum, often associated with forceps delivery and vacuum extraction, Wong, 2001, pp. 246-247).
- Unrecognized hemolytic disease (i.e., ABO or Rh blood incompatibility).
- Glucose-6-phosphate dehydrogenase (G6PD deficiency). This is a genetic disorder.
- Genetic or ethnic risk factors that include history of siblings with jaundice and East Asian or Mediterranean decent.

According to the CDC, the mortality rate of hyperbilirubinemia is 10%; however, the numbers of children affected by the morbidity of this disorder is unknown (CDC, 2001). The long-term outcomes of these children can be severe and the general pattern of injury involves the child developing cerebral palsy with athetoid movements, gaze abnormalities, sensorineural hearing loss, severe speech impairments and, in some cases, mental retardation. Some children may not be cognitively impaired but may exhibit a "locked in" syndrome with motor and communication impairments.

Implications for the Life Care Planner

In the pediatric medical legal arena, kernicterus cases are being seen with more frequency. Children suffering from kernicterus tend to have complex long-term needs, and, as previously stated, they tend to have severe movement disorders with motor coordination problems. When a life care planner receives a case of a child with bilirubin encephalopathy or kernicterus, the life care planner would benefit by becoming or being familiar with pediatric serv-

ices that can be delivered locally as well as services that the family may need to travel to get to and develop the life care plan appropriately. For life care planners who routinely develop pediatric life care plans, it is likely they may encounter a bilirubin encephalopathy/kernicterus case. Children with this diagnosis frequently have hearing loss or are deaf, and, in some cases, are candidates for cochlear implants. If so, the life care planner will most likely need to consider adding the cost of a cochlear evaluation and the implant and/or follow-up and maintenance in the life care plan. (See Appendix A, Selected Sections from a Sample Life Care Plan). In addition, this group of children has significant communication challenges requiring specialized therapy for communication with technical augmentative communication needs. For these children, the life care planner will want to consider including an evaluation for augmentative communication as well as appropriate technology, maintenance and follow-up training and evaluation throughout the child's life. (See Appendix A, Selected Sections from a Sample Life Care Plan).

These issues are the tip of the iceberg as the level of need for children with bilirubin encephalopathy or kernicterus and support for their families is often very extensive. Children with bilirubin encephalopathy or kernicterus could have future medical needs totaling into the millions of dollars. Developing a life care plan for these children can be taxing and difficult and it may best be done by an experienced life care planner with a strong pediatric background and knowledge of this diagnosis. (See Appendix A, Selected Sections from a Sample Life Care Plan).

The same holds true for treating physicians. It is the experience of this author that children with kernicterus and conditions such as cerebral palsy often benefit from the treatment of experienced pediatric physical medicine and rehabilitation (PM&R) physicians as this group of physicians is trained in long-term habilitation as well as rehabilitation of children. Some children with the diagnosis may best be served by a physician other than or in addition to a pediatric physiatrist, especially based on availability of such specialist to a particular child or family. Additionally, based on the child's medical needs, there may be several other medical and non-medical specialty services required such as physical and/or occupational therapy evaluation and treatment for associated problems such as movement disorder, and speech therapy for communication and/or oral motor needs. Consistent with the published life care planning methodology (International Academy of Life Care Planners, 2001), the life care plan should be developed to address the needs of the particular child and family as a result of the injury. This article simply lists a few suggestions to assist with the life care plan development.

As with most pediatric cases, pediatric specialty services should be considered and planned for in the life care plan. Additionally, adult specialty services must be considered in adult years. Keep in mind that services that may be available for adults may be more of a challenge to find for pediatric cases. For example, home care services for infants and children, especially private duty services, are often less readily available than adult home care services. Thus, the life care planner must be willing and able to seek out appropriate services for the child's age and developmental stage when developing the plan. (See Appendix A, Selected Sections from a Sample Life Care Plan).

Practice Guidelines for Medical Care

Although the life care planner generally is not involved with causation when developing a life care plan, being familiar with practice guidelines for medical care may be beneficial by providing the life care planner some background. In October 1994, the AAP produced a prac-

tice parameter for the management of hyperbilirubinemia in the healthy term newborn (AAP, 1994). This guideline was based on the assessment of jaundice and evaluation for possible hemolytic disease as well as post-discharge follow-up. In 2001, the AAP subcommittee on hyperbilirubinemia had a goal to bring the issue of kernicterus to the attention of the pediatric community (AAP, 2001). In 2004, the clinical practice guidelines for the treatment of the infant with hyperbilirubinemia were revised as a result of the AAP subcommittee on hyperbilirubinemia recommendations (AAP, 2004). This revision emphasizes the "importance of universal in-hospital screening for infants at risk for severe hyperbilirubinemia, medical follow-up within the first few days of hospital discharge (depending on the length of hospital stay and hyperbilirubinemia risk) and prompt intervention and treatment when jaundice is confirmed" (AAP News, 2004, p. 298). The recommendation applies to the care of infants at 35 weeks gestation or greater (AAP, 2004).

In April 2001, JCAHO released a sentinel event alert regarding kernicterus. The impetus for this was the resurgence of cases of bilirubin encephalopathy. The alert covered the need for understanding of risk factors, development of root cause analysis for identified cases, and noted changes for care in the newborn (JCAHO, 2001). The JCAHO examined kernicterus cases and identified patterns or root causes related to four patient care processes that were addressed. These four areas include:

- Patient assessment
- Continuum of care
- Patient and family education
- Treatment

With regard to patient assessment, JCAHO found that judging an infant's level of hyperbilirubinemia by using visual assessment of jaundice in the newborn was an unreliable method of assessment. This was a significant change as, historically, yellow skin color or jaundice had been a long-standing means of infant assessment. Additionally, JCAHO identified that caregivers had failed to recognize jaundice in an infant, or its severity, due to inadequate visual assessment of jaundice that led to the failure to measure total serum bilirubin levels. This failure to recognize jaundice occurred before initial discharge from the hospital after delivery as well as at the pediatrician's follow-up visit. The JCAHO also identified that that there was a pattern of failing to measure the bilirubin level for infants jaundiced in the first 24 hours of life (JCAHO, 2001).

In addressing the continuum of care, JCAHO noted that there were infants discharged in less than 48 hours of age with no follow-up within one to two days of discharge, especially with infants less than 38 weeks of gestation (JCAHO, 2001). It is well known that infants less than 38 weeks of gestation are at a higher risk group for the development of hyperbilirubinemia. The JCAHO also found that there was a failure to provide early follow-up and assessment of infants jaundiced prior to discharge. Additionally, JCAHO noted a failure to provide ongoing lactation support to breastfeeding mothers to ensure adequate breast milk intake.

Problems with patient and family education with newborn infants were also identified by JCAHO (JCAHO, 2001). Included were the failure to provide appropriate educational information about jaundice and failure to address concerns about poor infant feeding. Additionally, education regarding maternal lactation difficulties and providing information on the identification of changes in the activity or behavior of newborn infants was lacking.

Treatment of infants with hyperbilirubinemia, including failing to recognize, address, or

treat rapidly rising bilirubin levels also was found to be an identified pattern. In addition, the failure to aggressively treat severe hyperbilirubinemia in a timely manner with intensive phototherapy or exchange transfusion was noted. All of these areas potentially have implications for the life care planner who develops life care plans for children with kernicterus.

In August 2004, the JCAHO released a follow-up sentinal event publication that "recommends that all hospitals and health care professionals caring for newborns and infants both inside the hospital and after discharge from the hospital observe the recommendations cited in the updated clinical practice guideline" (JCAHO, 2004, p. 1) from the AAP. In litigation, the question of causation regarding the nurse or nurses caring for an infant may be in question. The National Association of Neonatal Nurses (NANN) weighed in on the concern with kernicterus on August 7, 2003 by issuing an approved position statement (NANN Position Statement #3040, 2003). The position statement discusses the prevention of bilirubin encephalopathy and kernicterus in newborns. In the statement, NANN stresses that neonatal nurses must be proactive in the assessment and management of hyperbilirubinemia in the newborn. NANN also states that parents should be educated about the risks of hyperbilirubinemia as well as what will occur if the condition is left untreated. Parents should be made aware of the need to have their infants closely followed after discharge. Finally, NANN notes that nurses must take steps to increase awareness and identify strategies within their institutions and practice to enhance process(es) of diagnosis and management of hyperbilirubinemia (NANN Position Statement #3040, 2003). The issuance of this position statement placed a burden of accountability for neonatal nurses practicing in the field to a standard in caring for the infant with hyperbilirubinemia. These nurses are to be proactive with assessment and management of hyperbilirubinemia in newborn infants.

Concurrent with changes in clinical practice guidelines, the support group, PICK, was developed in late 2000 by mothers of children with severe cerebral palsy resulting from kernicterus. Since its inception, this group has been very active with constructively advocating for involvement from JCAHO and the CDC. The PICK group has developed an informative web page that has links to the various agencies with position statements as discussed in this article. (See Appendix B, Resources for the Life Care Planner). Some of the families in PICK have been involved in litigation with regard to the bilirubin encephalopathy of their children and it is noted that there have been high dollar life care plans developed for some of these children (www.PICK.org, 2005).

Conclusion

A high level of bilirubin is known to be damaging to some infants and can cause bilirubinemia encephalopathy or kernicterus. Bilirubin encephalopathy is considered a neurodevelopmental disability and one objective for Healthy People 2010 is to reduce or eliminate preventable neurodevelopmental disabilities in infancy (Healthy People 2010, 2005). The CDC is funding the development of kernicterus research and prevention programs in Pennsylvania as well as a center in New Jersey (CDC, 2004). The Robert Wood Johnson Medical School Kernicterus Research and Prevention Center in New Brunswick, NJ is going to conduct monitoring activities and an epidemiological study. Clearly, efforts to prevent hyperbilirubinemia encephalopathy continue.

If not treated appropriately and timely, the outcome for a child with bilirubin encephalopathy or kernicterus can be on a continuum of movement and communication disorders often requiring long-term, life-long intervention. Life care planners with experience in developing

pediatric care plans and knowledge of the issues specific to children with this diagnosis are in a unique position to apply their skills to the development of a life care plan that addresses the individual child and family needs.

Data presented in this article show that the incidence of kernicterus appears to be on the rise and the life care planner with a specialty in this area can be expected to also see an increase in referrals for this client population. As a tool that outlines future needs, the life care plan can be extremely useful to plan for the client's individual and very specific current and future health care needs as related to the kernicterus.

Appendix A, Selected Sections from a Sample Life Care Plan*

* For Educational Purposes Only. The below selected sections from a sample life care plan are not intended to be inclusive of all potential services recommended for a child with kernicterus. Every child is an individual with needs based upon his/her disability and its effects upon his/her physical, mental, emotional and functional abilities. Each case should be evaluated individually with regard to the child's specific needs.

Medical Care						
Service:	**Age Initiated:**	**Through Age:**	**Estimated Cost of Visit:**	**Frequency of Visit:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
Pediatrician	3	20	105.00	1-2 times per yr related to Dx	157.50	0.00
Internal medicine	21	21	222.00	1 time related to Dx	0.00	222.00
	21	Lifetime	105.00	1 time per yr related to Dx	105.00	0.00
Neurologist for seizure disorder	3	20	279.50	2-3 times per yr	698.75	0.00
	21	21	222.00	1 time	0.00	222.00
	21	Lifetime	105.00	2 times per yr	210.00	0.00
Physiatrist	3	20	105.00	2-3 times per yr	262.50	0.00
	21	21	222.00	1 time	0.00	222.00
	21	Lifetime	105.00	1 time per yr	105.00	0.00
Pulmonologist	3	20	105.00	1-2 times per yr	157.50	0.00
	21	21	222.00	1 time	0.00	222.00
	21	Lifetime	105.00	1 time per yr	105.00	0.00
ENT	3	Lifetime	105.00	1 time per yr	105.00	0.00
Audiologist	3	4	218.00	2 times per yr	436.00	0.00
	5	6	218.00	1 time per yr	218.00	0.00
	7	Lifetime	142.00	1 time per yr	142.00	0.00
Orthopedist	3	20	105.00	3-4 times per yr	367.50	0.00
	21	21	222.00	1 time	0.00	222.00
	21	Lifetime	105.00	1 time per yr	105.00	0.00
Gastroenterologist	3	20	105.00	2 times per yr	210.00	0.00
	21	21	222.00	1 time	0.00	222.00
	21	Lifetime	105.00	1 time per yr	105.00	0.00
Dentist	3	20	46.00	1-2 times per yr related to Dx	69.00	0.00
	21	Lifetime	65.00	1-2 times per yr related to Dx	97.50	0.00
Urologist	3	Lifetime	222.00	2-3 times in lifetime	0.00	555.00
Rationale:						
Routine and periodic evaluations by the above physicians will be necessary due to the child's current diagnosis of						

Medical Care						
Service:	**Age Initiated:**	**Through Age:**	**Estimated Cost of Visit:**	**Frequency of Visit:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
kernicterus to assist in maintaining and/or improving his/her medical condition, quality of life and in the prevention of potential complications. Children who have chronic kernicterus/bilirubin encephalopathy demonstrate classic symptoms including movement disorder, auditory losses, visual impairment and impaired dentition.						

Evaluations						
Description:	**Age Initiated:**	**Through Age:**	**Estimated Cost of Visit:**	**Frequency:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
Developmental evaluations	3	18	764.00	1 time every 3 yrs	254.67	0.00
Physical therapy	3	Lifetime	110.00	1 time per yr	110.00	0.00
Occupational therapy	3	Lifetime	110.00	1 time per yr	110.00	0.00
Speech therapy	3	20	110.00	1 time per yr	110.00	0.00
Augmentative communication & technology evaluation	3	Lifetime	564.00	2-3 times	0.00	1,410.00
Neuropsychological evaluation	8	Lifetime	1,375.00	2-3 times in lifetime	0.00	3,437.50
Rationale:						
A physical therapy evaluation will assess gross motor skills, mobility such as gait or wheelchair needs, balance, transfer skills, range of motion, endurance and coordination of limbs and trunk, need for physical modalities such as superficial or deep heat, electrical stimulation, cold therapy and/or traction, need for specific orthoses and adaptive equipment such as wheelchairs and gait aids, and make the necessary recommendations required to maintain/improve medical and functional status. An occupational therapy evaluation will assess fine motor skills; ability to perform activities of daily living such as dressing bathing, hygiene and eating; range of motion of upper extremities and cervical area; need for orthoses (braces) and or splints for the upper extremities; need for adaptive equipment and home modifications; and make the necessary recommendations. Speech therapy evaluation will assess and make recommendations to treat problems with communication, swallowing and assist with cognitive retraining. Augmentative and alternative communication (AAC) include all forms of communication that enhance or supplement speech and writing. A method of AAC can enhance or replace conventional forms of expression. The AAC evaluation will assess current communication abilities, needs and goals; physical abilities and limitations; current communication status; perceptual-cognitive language abilities; symbolic skills; literacy skills; behavioral considerations; environmental considerations; and the potential for using a range of AAC options. The client will be assessed using different types of communications systems (no-tech and/or high tech if appropriate) to determine the most appropriate one. A neuropsychological evaluation will assess the relationship between the brain and behaviors including the use of psychological tests and assessment techniques to identify specific cognitive and behavioral deficits and recommend rehabilitation strategies for remediation. It will assess cognitive and behavioral functions including: intelligence; problem solving and conceptualization; planning and organization; attention, memory and learning; language; academic skills; perceptual and motor abilities; and emotions, behavior, and personality.						

Therapies						
Description:	**Age Initiated:**	**Through Age:**	**Estimated Cost of Visit:**	**Frequency:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
Physical therapy	3	20	110.00	1-2 times per wk	7,920.00	0.00

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Service:	**Age Initiated:**	**Through Age:**	**Estimated Cost of Visit:**	**Frequency of Visit:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
(supplemental)				(48 wks)		
	21	Lifetime	110.00	4 sessions per yr	440.00	0.00
Occupational therapy (supplemental)	3	20	110.00	1-2 times per wk	7,920.00	0.00
	21	Lifetime	110.00	4 sessions per yr	440.00	0.00
Speech therapy (supplemental)	3	20	110.00	2 times per wk	10,560.00	0.00
Augmentative communication training	3	Lifetime	1,400.00	2 times	0.00	2,800.00
Therapeutic riding	3	20	45.00 per session	1-2 times per wk	3,375.00	0.00
Nutritional counseling	3	Lifetime	92.00	every 4 mo	276.00	0.00
Individual counseling for family			150.00 (5)	Initial visit per ea family member	0.00	750.00
mother	3	Lifetime	95.00 per session	5-10 sessions per regimen (2 regimens)	0.00	1,425.00
father	3	Lifetime	95.00 per session	5-10 sessions per regimen (2 regimens)	0.00	1,425.00
siblings	3	Lifetime	95.00 per session per sibling	5-10 sessions per regimen per sibling (1 regimen)	0.00	712.50 per sibling

Rationale:

The above therapies are required to maintain and improve current status and to aid in the prevention of potential complications.

Physical and occupational therapy are provided by the school system under the IDEA but are only educationally based. Because of this, the above supplemental regimens have been included to maintain and/or improve quality of life, medical condition and in the prevention of potential complications.

Physical and occupational therapy will implement the changes and recommendations made to meet the client's ever changing needs. At times, the client may require more therapy than at other times due to changes in medical and functional status and musculoskeletal system resulting from growth, lack of mobility, weight bearing, spasticity, pain control, overuse and as the degenerative effects of aging occur. In addition, the therapies will initiate changes made to the client's home exercise program, initiate training and re-training.

Family counseling is recommended to assist the client's family in dealing with the client's disability, its impact upon the family, changes in their lifestyle, and in maintaining a healthy family unit.

Therapeutic riding/hippotherapy is a treatment approach that uses the movement of the horse based on principles concerning neuromotor function and sensory processing. It is a functionally relevant activity that can address impairments of tone, range of motion, timing, attention, arousal, coordination, balance and postural control. Not only is hippotherapy expected to be beneficial to the client's medical condition but is expected to also provide the client with enjoyment through recreational activities.

Nutritional counseling is important for maintaining skin integrity, bone growth and changes, elimination and overall well

Medical Care						
Service:	**Age Initiated:**	**Through Age:**	**Estimated Cost of Visit:**	**Frequency of Visit:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
being. Due to the kernicterus, the client has been diagnosed with failure to thrive and will require close observation to maintain a healthy nutritional status.						

Aids for Independent Living						
Description/Item:	**Age Initiated:**	**Through Age:**	**Estimated Cost:**	**Replacement:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
Shower commode chair	3	Lifetime	1,325.00	every 3 yrs	441.67	0.00
Hand held shower with diverter valve	3	Lifetime	43.00	every 3 yrs	14.33	0.00
Computer with CPU, monitor, printer and software in addition to adaptive technology	6	Lifetime	2,000.00	every 3-5 yrs	500.00	0.00
Communication board with button, 1 picture	3	5	299.00	1 time	0.00	299.00
Boardmaker	3	5	299.00	1 time	0.00	299.00
Dynavox (augmentative communication device)	6	Lifetime	7,295.00	every 5-7 yrs	1,215.83	0.00
Dynavox warranty	6	Lifetime	1,437.50	every yr	1,437.50	0.00
Dynavox battery	6	Lifetime	150.00	every yr	150.00	0.00
Internet access	6	Lifetime	15.00 per mo	1 time per mo	180.00	0.00
Rationale:						
The above equipment and software will aid the client with communication, quality of life and independence.						

Orthotics/Prosthetics						
Description/Item:	**Age Initiated:**	**Through Age:**	**Estimated Cost:**	**Replacement:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
Bilateral custom solid ankle AFOs	3	12	1,000.00 per pr	1 time every 1-2 yrs	1,500.00	0.00
	13	20	1,000.00 per pr	1 time every 3 yrs	333.33	0.00
	21	Lifetime	1,000.00 per pr	every 5 yrs	200.00	0.00
Benik Vest (2)	3	12	125.00 ea	1 time every 1-2 yrs	166.67	0.00
	13	Lifetime	125.00 ea	1 time every 3 yrs	83.33	0.00
Wrist splints (2)	3	Lifetime	97.00 ea	1 time per yr	194.00	0.00
Cochlear speech processor	3	Lifetime	6,000.00	2-3 times in lifetime	0.00	15,000.00
Re-chargeable AA batteries	3	Lifetime	12.00 per pack	2 packs every yr	24.00	0.00

Medical Care						
Service:	**Age Initiated:**	**Through Age:**	**Estimated Cost of Visit:**	**Frequency of Visit:**	**Estimated Annual Cost:**	**Estimated One Time Cost:**
Battery charger	3	Lifetime	60.00	every 1-2 yrs	40.00	0.00
Accessory kit, includes cables, etc.	3	Lifetime	595.00	every 1-2 yrs	396.67	0.00
Cochlear implant insurance	3	Lifetime	190.00	1 time per yr	190.00	0.00
Maintenance agreement (2 yr)	3	Lifetime	645.00	2-3 times	0.00	1,612.50
Rationale:						
AFOs (ankle foot orthoses) and wrist splints are for proper positioning and maintaining proper alignment as well as assisting in the prevention of potential complications such as contractures. The Benik vest provides trunk support, assisting with proper positioning and alignment and aiding in the prevention of scoliosis. Proper trunk positioning and support assists with digestion and breathing. The Cochlear speech processor along with the cochlear implant provide the individual with neuro hearing loss the ability to hear. The speech processor will require periodic replacement over a lifetime. The accessories associated with the speech processor will require replacement routinely. *The client already has the cochlear implant. The surgery, including device, costs approximately $50,055.00. *It is important to address follow-up, specific testing, replacement, etc. with the specialist.						

Appendix B, Common Kernicterus Resources for the Life Care Planner

1. Centers for Disease Control, www.CDC.gov
2. www.kernicterus.org
3. Parents of Infants and Children with Kernicterus, www.pickonline.org
4. American Academy of Pediatrics, www.AAP.org
5. Joint Commission on Accreditation of Healthcare Organizations, www.JCAHO.org
6. Healthy People 2010, www.healthypeople.gov
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