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Life Care Planning in Wrongful Birth Cases

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Abstract

Fewer than 10 wrongful birth lawsuits are filed in the United States every year. Such lawsuits generally involve parents undergoing prenatal testing for birth abnormalities and being advised by the clinic that no abnormalities were found. It is only after the birth of their child that parents learn their child has a disabling condition. The following represents a case study involving a wrongful birth case that went to trial. A life care plan was designed in regard to the case involving now four-year-old Kalanit Levy who was diagnosed with Down syndrome. An Oregon jury delivered an almost $3 million wrongful birth verdict in favor of the Levys. The life care plan prepared for this case is discussed.

Introduction

When she was only 15 months old, Kalanit (Kali) Levy was referred for development of a life care plan in September 2008 in a "wrongful birth" lawsuit against the physician and laboratory who allegedly failed in their prenatal testing to diagnose Kali with Down syndrome. Before the two year statute of limitations would occur in June 2009, the plaintiff attorney had attempted mediation with the defense attorney prior to filing the case. Mediation was not successful and a complaint was filed by the plaintiff in late May 2009. The trial occurred in Portland, Oregon, during 9 days in March 2012.

Prenatal Screening and Wrongful Birth

Prenatal screening has been widely accepted in the United States since the late 1960s and is designed to help couples make informed reproductive choices (DeJong, de Die-Smulders, Frints, de Wert, 2010; Greeley, 2011). Non-invasive screening such as ultrasound is used to determine if there is a need for additional testing. The two forms most commonly used at present are amniocentesis and Chorionic Villus Sampling (CVS), both invasive procedures. Amniocentesis requires a needle to be inserted through the mother's abdominal wall then through the uterine wall, and into the amniotic sac. The physician punctures the sac using ultrasound guidance and extracts about 20 ml of amniotic fluid. Fetal cells are separated, grown in a culture medium, fixed and stained on a slide, and examined under a microscope to determine chromosomal abnormalities.

Chorionic Villus Sampling can be performed earlier than amniocentesis. As in amniocentesis, a sample of the chorionic villus (tiny finger-shaped growths in the placenta) is taken by needle through the mother's abdomen under ultrasound guidance into the placenta and a biopsy sample is extracted. Alternatively, a very thin catheter is inserted through the vagina and cervix and into the placenta where a biopsy sample is collected. DNA, chromosomes and

certain chemical markers are studied under the microscope similar to that of the amniocentesis sample. Because both CVS and amniocentesis are invasive, there are some risks such as bleeding, infection miscarriage, and rupture of membranes. The Reproductive Genetics Institute (2012) cites 99% accuracy in CVS. About 1% of the time the results will not allow the physician to establish with certainty whether the baby's chromosomes are normal, and further testing such as amniocentesis is performed.

Down syndrome is the most frequently occurring chromosomal disorder (Irving, Basu, Richmond, Burn, & Wren, 2008). It is a genetic condition in which a person has 47 chromosomes instead of the usual 46 (Trisomy 21). In mosaic Down syndrome, some cells have a total of 46 chromosomes and other cells have an extra copy of chromosome 21. The existence of two chromosomal abnormalities in the same individual is rare but some children have been reported to have Down syndrome (trisomy 21) plus XYY and some with Trisomy 21 plus XXY. This is called double aneuploidy (Eid, Shawabkeh, Hawamdeh, & Kamal, n.d.). Green (2012) cites studies indicating that 89% or more of expectant mothers who learn their child would have Down syndrome chose to abort the pregnancy.

The Levy Claim

Once the complaint was filed, the defense attorney filed a motion in January 2010 to dismiss the wrongful birth claim stating "Oregon does not recognize a claim by parents for 'wrongful birth' for damages for all expenses of raising and caring for a genetically unhealthy child, and no claim for 'wrongful life' may be stated on behalf of Kali Levy." On August 3, 2010, Multnomah County Circuit Court Judge Marilyn Litzenberger denied this motion, stating "wrongful birth' claims are recognized in some form in the majority of states that have considered the issue, although there is no case directly addressing this claim in Oregon." Judge Litzenberger continued, "This can be distinguished from 'wrongful life' claims, which are brought by a child, or on behalf of a child, and assert that the child's very coming into being was a harm to the child because of some physical, mental or social disability. Unlike 'wrongful birth' claims, very few jurisdictions have recognized claims for 'wrongful life." No case in Oregon law has thus far addressed 'wrongful life' claims. In sum, the 'wrongful birth' case was allowed to proceed; the 'wrongful life' claim was not.

Deborah and Ariel Levy had two sons, the oldest age 4 years and the younger only 14 months when in October 2006 they were surprised to learn of Deborah's unexpected pregnancy. Ms. Levy was nearly 35 years old. The couple sought prenatal testing to determine if the fetus was healthy and had any chromosomal abnormalities. Ms. Levy underwent screening about her 8th week of pregnancy which revealed the unborn child was at increased risk for Down syndrome. As such, Chorionic Villus Sampling (CVS) was recommended, and the Levys were informed of the reliability of CVS testing. The test cost was $2,500 out-of-pocket, and the Levys were subsequently informed that the fetus did not have Down syndrome. Despite the unplanned pregnancy, both parents were reportedly happy to be expecting a healthy daughter.

Before Kali was born, Ms. Levy underwent additional ultrasound screening which revealed once again findings or markers consistent for a child with Down syndrome. However, the Levys were again reassured by the physicians that these markers were not reliable given the results of the earlier CVS.

Within days of Kali's birth it appeared obvious that she indeed had Down syndrome, and testing confirmed this observation. During trial, jurors learned that the Levys have since faced overwhelming costs for medical appointments, diagnostic tests, and treatments such as speech

and physical therapy. At four, Kali remains in diapers. She occasionally eats or throws her feces if not closely supervised. In pre-school and at home, she must have one-on-one attention. The Levys have been advised that Kali will never be able to live independently.

In trial the plaintiff attorney presented experts from Loma Linda University in California and from Pittsburgh who testified regarding deficiencies in the CVS testing process performed on Ms. Levy. They testified the physician removed and tested only the mother's womb tissue and not tissue directly from the fetus. Defense attorneys presented testimony that the CVS produced only normal cells because Kali's diagnosis was mosaic Down syndrome, in which a significant number of the cells do not contain the extra 21st chromosome. Each side's medical experts presented contradictory opinions and cited the other's experts as ill-informed during trial.

Kali's Life Care Plan

The life care plan prepared in November 2008 was different than the exhibits ultimately prepared and testified to in March 2012. A portion of the lay-out of the 2008 life care plan can be found in Table 1. A useful source in this case was Cohen (2002) *Health Care Guidelines for Individuals with Down Syndrome-1999 Revision.*

Plaintiff Arguments

The plaintiff attorney wanted to save the Levy family the expense and trauma of litigation and attempted to mediate with the laboratory and physician before filing suit. A life care planner was retained as was a medical expert who verified that it was clear the CVS testing results had been misinterpreted. Unfortunately, mediation was not successful. The complaint was filed by the plaintiff attorney on 5/29/09. The defense attorney, as mentioned, responded on 1/25/10, seeking dismissal. The plaintiff responded in a memorandum on 2/23/10.

(Table 1 next page)

Table 1

Sample Future Medical Routine Care

Childhood (1 yr – 12 yrs)	Purpose	Age/yr initiated	Age/yr stop	Per yr treatment	Base cost/yr
Child Neurologist or developmental Pediatrician	General pediatric & neurologic exams for spinal cord compression, deep tendon reflexes, gait	1/2008	12/2019	2x/yr; $390 - $520/eval; aver = $455 each	$910
Pediatric Cardiologist	Monitor cardiac function for complications	1/2008	12/2019	1x/yr	$244
Etc.					
Adolescence (13 – 18 yrs)	Purpose	Age/yr initiated	Age/yr stop	Per yr treatment	Base cost/yr
Neurologist or developmental Pediatrician	Purpose cited as above	13/2020	18/2025	1x/yr	$455
Adolescent Practitioner specialized in developmental disabilities	Address issues of sexuality	13/2020	18/2025	1x/yr	$349
Etc.					
Adulthood (19 yrs to LE)	Purpose	Age/yr initiated	Age/yr stop	Per yr treatment	Base cost/yr
PM&R Physician	Monitor for loss of independence, behavioral changes, mental health problems, dementia	19/2026	LE	1x/yr	$165
Guardianship services	Provide assistance for Kali's independence	19/2026	LE	20-40 hrs/mo @ $95/hr	$22,800 - $45,600/yr
Etc.					

Total value in $2008 for the initial life care plan was estimated for three different life expectancies. Future medical expenses using a health statistical life expectancy of 81 years was $3,082,428. A second analysis with a reduced life expectancy of 71 years totaled $2,602,018. The third scenario of future medical expenses using a further reduced life expectancy to age 61 totaled $2,121,608.

These medical expenses included physician, cardiologist, orthopedist, MRI or CT scans, ophthalmologist, lab tests, respiratory syncytial virus (RSV) vaccine, speech therapy, physical therapy, auditory evaluations, augmentive communications device, echocardiogram, subacute bacterial endocarditis (SBE) prophylaxis, nutrition evaluation, respite care, supportive counseling, and behavioral management techniques. Costs for private pre-school, a tutor and tuition for an extra year at the community college were also included. In addition, future lost wages for Kali's mother as a dental hygienist and for Kali's probable future earnings loses were estimated at $3,934,113.

Defense Arguments

With mediation having failed, the plaintiff attorney filed the complaint on 5/29/09. The defense responded in a motion against the plaintiff's complaint on 1/25/10, requesting dismissal of the lawsuit, stating there was no "breach of contract," that "wrongful birth" and "wrongful life" claims have not previously been recognized in Oregon, "nor should they be recognized now." The defense attorney wrote, "To date, Oregon has recognized only a claim for wrongful conception, *Zehr*, 318 OR 647 (failed sterilization procedure)." The defense attorney also sought to eliminate recovery for economic damages by Ms. Levy for her inability to return to work (lost wages) and for Mr. Levy for loss of consortium as well as a lost-wages claim for Kali Levy.

The defense attorney argued that Kali had mosaic Down syndrome resulting in the laboratory's inability to note this condition (Green, 2012).

The Court's decision

On 8/3/10 Judge Litzenberger issued her Opinion and Order, disallowing the plaintiff's claim for the mother's emotional distress and the father's loss of consortium claim. Judge Litzenberger ordered that the only claim that could go forward was the parents' claim for the economic expenses of raising and providing for a disabled child.

Life Care Plan Revision

Oregon is a state known as "trial by ambush." In Oregon circuit courts, experts are generally not revealed from plaintiff to defense and vice-versa until the first day of trial. It turned out the defense attorney did not call any witnesses to counter damage testimony. As such, and due to the 2008 recession and the controversy over "wrongful birth" lawsuits, the plaintiff attorney chose to present economic damages in a conservative manner. He strategized that a conservative life care plan would either prevent the defense from calling a life care planner or would allow the defense life care planner to agree with my plaintiff life care plan.

The life care planning exhibits prepared for the March 2012 trial removed any items that were no longer necessary for Kali's care. For example, since she was shown not to have a heart defect, cardiology evaluations were removed from the life care plan. In addition, to simplify the life care plan for ease of explanation and understanding by the jury, instead of separating childhood, adolescence, and adulthood developmental periods, the exhibits were simplified as shown in Table 2.

Table 2

Sample Future Medical Routine Care

Treatment	Purpose	Age/yr initiated	Age/yr stop	Per yr treatment	Base cost/yr
Child neurologist or developmental pediatrician	General pediatric & neurologic exam including evaluation for signs of spinal cord compression, deep tendon reflexes, gait, Babinski sign	4/2012	12/2019	2x/yr; $390 - $520/eval; aver = $455 ea	$910
Child neurologist or developmental pediatrician	General pediatric & neurologic exam including evaluation for signs of spinal cord compression, deep tendon reflexes, gait, Babinski sign	13/2021	18/2026	1x/yr	$455
PM&R Physician	Monitor for loss of independence, behavioral changes, mental health problems, symptoms of dementia as aging, seizures, incontinence	19/2026	LE	1x/yr	$165
Etc.					

The total amount of this life care plan, in 2012 dollars using a simple Excel spreadsheet, was $2,898,438 to $4,300,038. An expert economist testified to inflation and discount rates.

The Levy Verdict

The jury's verdict overall was that they decided the laboratory was negligent on multiple fronts. They concluded "that employees, including the doctor who took the sample and lab workers who analyzed it, failed to communicate, leading to the erroneous result" (Green, 2012). The jury agreed that Kali's future medical care needs were significant, and awarded $2.9 million.

Selective Abortion Controversy

There continues to be moral and bioethical controversy in regard to selective abortion when parents learn their pregnancy will result in a child with abnormalities and they subsequently make the difficult decision to abort. It is also difficult to bring such an action into the public court system. The trial judge, Karin Immergut, ordered cameras excluded from the courtroom. Despite the Levy's attorney showing their love for Kali, the Levys incurred death threats during and after the trial. Green (2012) reported that, "Despite the critics who called them cold, unloving parents and the extremists who wished them dead, the attorney for Deborah and Ariel Levy say the couple were determined to go ahead with a trial to secure a financial future for their daughter."

For developed countries, such selective abortion is common. The purpose of prenatal screening has been to offer a choice to expectant parents after the advent of legal abortion. Some countries offer such prenatal screening but abortion is not legal, so there is a 'therapeutic gap,' especially Latin American (Roman Catholic majority) countries (Ballantyne, 2009). While these are developed countries, the law does not provide access to safe and legal abortion. Regardless which country, the issue of selective abortion specifically is highly contested, an ethical conundrum, and differs morally for those with religious views of life beginning at conception or later (ensoulment).

In Iran, laws now permit abortion before the time of the Islam belief of ensoulment (16 weeks) with appropriate permissions (Aramesh, 2009). Rules developed by Iran's Forensic Medicine Organization (FMO) contain 29 fetal and 32 maternal abnormalities or diseases permitting abortion prior to 16 weeks of gestation. Down syndrome is not among these.

The Japanese culture views disability as a personal or familial issue and are often shamed when a child is born with a disability. If the woman is precluded from making an informed choice when prenatal screening is inadequately performed or communicated and the mother has a child with Down syndrome, she and her family are sometimes ostracized by her family and society. Since Asian culture in general sometimes views disability as an embarrassment and attempt to keep the disability private within the family, the child sometimes does not obtain the services for which he or she is entitled (Marini, 2012).

Conclusion

Despite the ongoing heated debate regarding selective abortion and attempted character assassination of otherwise loving parents who would have knowingly elected to abort a child born with a severe disability, the core issues of "wrongful birth" lawsuits are essentially medical malpractice due to negligence. Parents arguably should not be expected to assume the lifetime medical costs for a child they could have had the option to abort if correctly advised. Life care planners must follow the same standard protocol and methodology in developing pediatric life care plans for infants with congenital disabilities. Since many women are now having children into their 30s and 40s, prenatal testing for genetic abnormalities and the option to abort is likely to become more common.

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