

Exhibit A

**Contacts for State Legal Requirements Regarding Ashley
Treatment**

Contacts for State Legal Requirements Regarding Ashley's Treatment

All contacts below have agreed to be listed here as a resource regarding the legal requirements related to the Ashley's Treatment in their states.

Alabama

Alabama Disabilities Advocacy Program

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Alaska

Disability Law Center of Alaska

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California

Protection & Advocacy, Inc.

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Colorado

The Legal Center for People
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Connecticut

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Georgia

Georgia Advocacy Office

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Iowa

Iowa Protection and Advocacy Services,
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Kansas

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Kentucky

Kentucky Protection and Advocacy

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Louisiana

Louisiana Advocacy Center

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Maine

Disability Rights Center

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Michigan

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Minnesota

Minnesota Disability Law Center

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Mississippi

Mississippi Protection and Advocacy System

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New Hampshire

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New Jersey

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North Dakota Protection & Advocacy
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South Carolina

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South Dakota Advocacy Services

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Virginia Office for
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Washington

The legal requirements for Washington
State are discussed in the report.

West Virginia

West Virginia Advocates

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Exhibit B

Ashley's Mom and Dad, The "Ashley Treatment", Towards a Better Quality of Life for "Pillow Angels," (January 7, 2007)

The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels”

Last updated: January 7th, 2007

By Ashley’s Mom and Dad
PillowAngel@hotmail.com

Ashley’s Story

Our daughter Ashley had a normal birth, but her mental and motor faculties did not develop. Over the years, neurologists, geneticists, and other specialists conducted every known traditional and experimental test, but still could not determine a diagnosis or a cause. Doctor’s call her condition “static encephalopathy of unknown etiology”, which means an insult to the brain of unknown origin or cause, and one that will not improve.

Now nine years old, Ashley cannot keep her head up, roll or change her sleeping position, hold a toy, or sit up by herself, let alone walk or talk. She is tube fed and depends on her caregivers in every way. We call her our “Pillow Angel” since she is so sweet and stays right where we place her—usually on a pillow.

Ashley is a beautiful girl whose body is developing normally with no external deformities; see [photos](#). She is expected to live a full life and was expected to attain a normal adult height and weight. Ashley being in a stable condition is a blessing because many kids with similarly severe disabilities tend to deteriorate and not survive beyond five years of age.

Ashley is alert and aware of her environment; she startles easily. She constantly moves her arms and kicks her legs. Sometimes she seems to be watching TV intently. She loves music and often gets in celebration mode of vocalizing, kicking, and choreographing/conducting with her hands when she really likes a song (Andrea Bocelli is her favorite – we call him her boyfriend). She rarely makes eye-contact even when it is clear that she is aware of a person’s presence next to her. Ashley goes to school in a classroom for special needs children, which provides her with daily bus trips, activities customized for her, and a high level of attention by her teachers and therapists.

Ashley brings a lot of love to our family and is a bonding factor in our relationship; we can’t imagine life without her. She has a sweet demeanor and often smiles and expresses delight when we visit with her, we think she recognizes us but can’t be sure. She has a younger healthy sister and brother. We constantly feel the desire to visit her room (her favorite place with special lights and colorful displays) or have her with us wanting to be in her aura of positive energy. We’re often huddled around her holding her hand, thus sensing a powerful connection with her pure, innocent and angelic spirit. As often as we can we give her position changes and back rubs, sweet talk her, move her to social and engaging places, and manage her



entertainment setting (music or TV). In return she inspires abundant love in our hearts, so effortlessly; she is such a blessing in our life!

To express how intensely we feel about providing Ashley with the best care possible, we would like to quote from a private email that we received from a loving mother with her own 6 year old "Pillow Angel": "In my mind, I have to be immortal because I have to always be here on Earth to take care of my precious child. Taking care of him is difficult, but it is never a burden. I am [his] eyes, ears and voice. He is my best friend, and I have dedicated my life to providing joy and comfort to him. To my last breath, everything I will ever do will be for him or because of him. I cannot adequately put into words the amount of love and devotion I have for my child. I am sure that you feel the same way about Ashley."

The chance of Ashley having significant improvement, such as being able to change her position in bed, let alone walk, is non-existent. She has been at the same level of cognitive and mental developmental ability since about three months of age.

Faced with Ashley's medical reality, as her deeply loving parents, we worked with her doctors to do all we could to provide Ashley with the best possible quality of life. The result is the "Ashley Treatment."

Summary

The "Ashley Treatment" is the name we have given to a collection of medical procedures for the improvement of Ashley's quality of life. The treatment includes growth attenuation through high-dose estrogen therapy, hysterectomy to eliminate the menstrual cycle and associated discomfort to Ashley, and breast bud removal to avoid the development of large breasts and the associated discomfort to Ashley. We pursued this treatment after much thought, research, and discussions with doctors.

Nearly three years after we started this process, and after the treatment was published in October, 2006 by Dr. Gunther and Dr. Diekema in a medical journal¹ that resulted in an extensive and worldwide coverage by the press² and dozens of public discussions³, we decided to share our thoughts and experience for two purposes: first, to help families who might bring similar benefits to their bedridden "Pillow Angels"; second, to address some misconceptions about the treatment and our motives for undertaking it.

A fundamental and universal misconception about the treatment is that it is intended to convenience the caregiver; rather, the central purpose is to improve Ashley's quality of life. Ashley's biggest challenges are discomfort and boredom; all other considerations in this discussion take a back seat to these central challenges. The "Ashley Treatment" goes right to the heart of these challenges and we strongly believe that it will mitigate them in a significant way and provide Ashley with lifelong benefits.

Unlike what most people thought, the decision to pursue the "Ashley Treatment" was not a difficult one. Ashley will be a lot more physically comfortable free of

menstrual cramps, free of the discomfort associated with large and fully-developed breasts, and with a smaller, lighter body that is better suited to constant lying down and is easier to be moved around.

Ashley's smaller and lighter size makes it more possible to include her in the typical family life and activities that provide her with needed comfort, closeness, security and love: meal time, car trips, touch, snuggles, etc. Typically, when awake, babies are in the same room as other family members, the sights and sounds of family life engaging the baby's attention, entertaining the baby. Likewise, Ashley has all of a baby's needs, including being entertained and engaged, and she calms at the sounds of family voices. Furthermore, given Ashley's mental age a nine and a half year old body is more appropriate and more dignified than a fully grown female body.

We call it "Ashley Treatment" because:

- 1- As far as we know Ashley is the first child to receive this treatment,
- 2- We wanted a name that is easy to remember and search for,
- 3- The name applies to a collection of procedures that together have the purpose of improving Ashley's quality of life and well-being. Growth attenuation is only one aspect of the treatment.

The "Ashley Treatment"

In early 2004 when Ashley was six and a half years old, we observed signs of early puberty. In a related conversation with Ashley's doctor, Ashley's Mom came upon the idea of accelerating her already precocious puberty to minimize her adult height and weight. We scheduled time with Dr. Daniel F. Gunther, Associate Professor of Pediatrics in Endocrinology at Seattle's Children's Hospital, and discussed our options. We learned that attenuating growth is feasible through high-dose estrogen therapy. This treatment was performed on teenage girls starting in the 60's and 70's, when it wasn't desirable for girls to be tall, with no negative or long-term side effects.

The fact that there is experience with administering high-dose estrogen to limit height in teen-age girls gave us the peace of mind that it was safe—no surprise side effects. Furthermore, people found justification in applying this treatment for cosmetic reasons while we were seeking a much more important purpose, as will be detailed below.

In addition to height and weight issues, we had concerns about Ashley's menstrual cycle and its associated cramps and discomfort. We also had concerns about Ashley's breasts developing and becoming a source of discomfort in her lying down position and while strapped across the chest area in her wheelchair, particularly since there is a family history of large breasts and other related issues that we discuss below. The estrogen treatment would hasten both the onset of the menstrual cycle and breast growth. Bleeding during the treatment would likely be very difficult to control.

It was obvious to us that we could significantly elevate Ashley's adult quality of life by pursuing the following three goals:

- 1- Limiting final height using high-dose estrogen therapy.
- 2- Avoiding menstruation and cramps by removing the uterus (hysterectomy).
- 3- Limiting growth of the breasts by removing the early breast buds.

The surgeon also performed an appendectomy during the surgery, since there is a chance of 5% of developing appendicitis in the general population, and this additional procedure presented no additional risk. If Ashley's appendix acts up, she would not be able to communicate the resulting pain. An inflamed appendix could rupture before we would know what was going on, causing significant complication.

Ashley was dealt a challenging life and the least that we could do as her loving parents and caregivers is to be diligent about maximizing her quality of life. The decision to move forward with the "Ashley Treatment" was not a difficult one for us as many seem to think. It was obvious that a reduction in Ashley's height (and therefore weight), elimination of the menstrual cycle, and avoidance of large breasts would bring significant benefits to her health and comfort. The only downside that we could think of was the surgery itself; however, the involved surgery is commonly done and is not complicated. Furthermore, we're fortunate to have access to one of the best surgical facilities and teams at Seattle Children's Hospital. If we were in a less developed locale or country with higher risk of surgery, we would have looked at this part of the analysis differently.

Since the "Ashley Treatment" was new and unusual, Dr. Gunther scheduled us to present our case to the ethics committee at Seattle Children's Hospital, which we did on May 5th 2004. The committee includes about 40 individuals from different disciplines and is evenly composed of men and women. After we presented our case we waited outside while the committee deliberated the issue. The committee chairman along with Doctor Diekema, ethics consultant, conveyed the committee's decision to us, which was to entrust us with doing the right thing for Ashley. There was one legal issue that we needed to investigate related to "sterilization" of a disabled person. Upon consultation with a lawyer specializing in disability law, we found out that the law does not apply to Ashley's case due to the severity of her disability, which makes voluntary reproduction impossible. The law is intended to protect women with mild disability who might choose to become pregnant at some future point, and should have the right to do so. Furthermore, "sterilization" is a side effect of the "Ashley Treatment" and not its intent.

The combined hysterectomy, breast bud removal, and appendectomy surgery was performed without complications in July 2004. Ashley spent four days in the hospital under close supervision, and thanks to aggressive pain control her discomfort appeared minimal. In less than one month, Ashley's incisions healed and she was back to normal; it's remarkable how kids heal so much quicker than adults. Ashley's Mom had had a C-section and knew first hand how Ashley would feel after surgery; thankfully, the recovery went much better than Mom anticipated.

Shortly after the surgery and recovery, we started the high-dose estrogen therapy. We've just completed this treatment after two and a half years. During this whole period, we have observed no adverse consequences.

Following we provide more details about the different aspects of the treatment and the related benefits.

Limiting Final Height Using High-Dose Estrogen

After the surgery, we started Ashley on a high-dose estrogen therapy using derma-patches that we change every three days. Estrogen advances bone age until separate growth plates in the bones fuse together, see [photos](#), halting growth and determining the extent of height. This occurs in both boys and girls.

Dr. Gunther sees Ashley every three months to monitor:

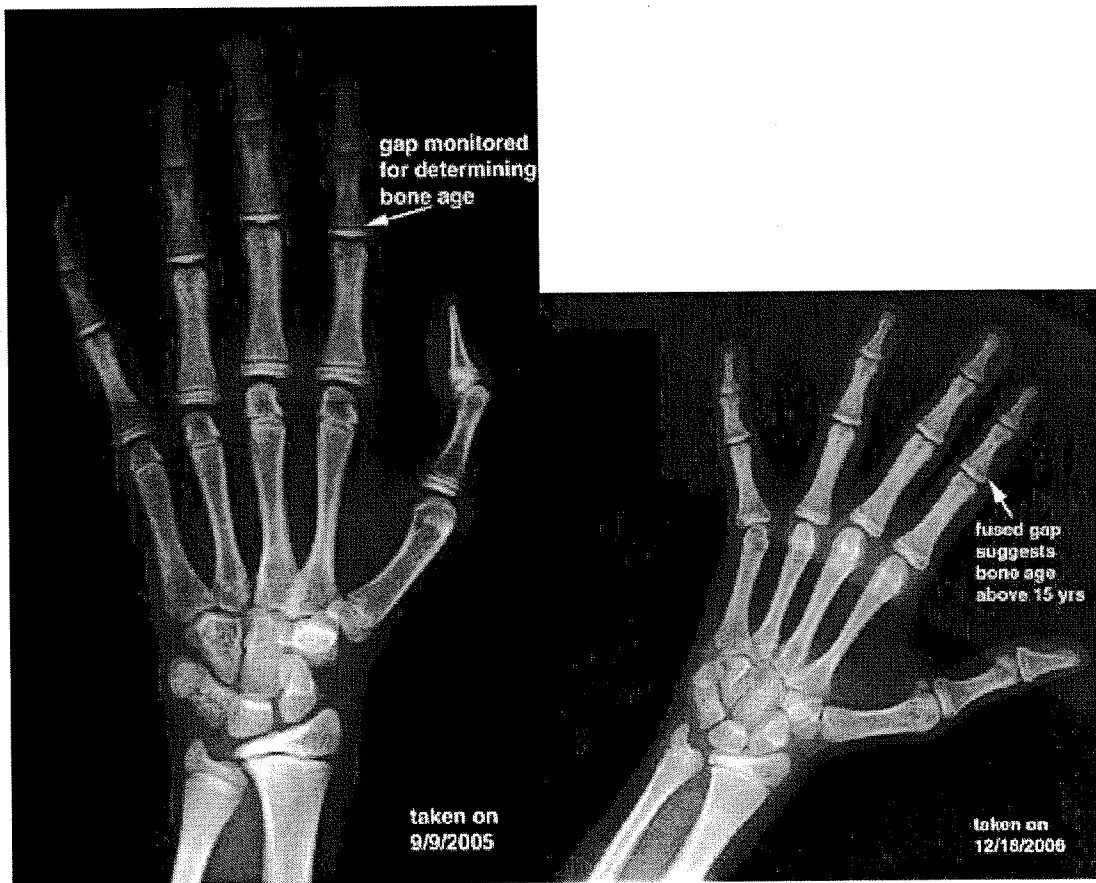
- Weight and height
- Bone age, by comparing her hand X-ray to a set of reference photos
- Estrogen level, and other tests, through blood work

Based on Dr. Gunther's analysis, predictions, and estimates, this treatment is expected to reduce Ashley's untreated height by 20% and weight by 40%. If we had started the treatment at a younger age, the benefits to Ashley would have been greater.

More specifically, at this point Ashley is 53" (4' 5"), (average for a nine and a half year old girl), and has a bone age of 15 years (see [photos](#)), which implies that she is about 99% of her height. When Ashley was 6 years and 6 months old she was 48" (4' 0"), (75th percentile for her age at the time). Normal growth would have resulted in an adult height in the neighborhood of 66" (5' 6"), (Ashley's Mom and Dad, are 5' 9" and 6' 1", respectively). Therefore, the treatment is expected to produce a height reduction of 13 inches (or 20%). Average weight of a 4' 5" woman is 75 lbs, while the average weight of a 5' 6" woman is around 125 lbs, so the treatment is expected to produce a weight reduction of 50 pounds (or 40%).

We are currently near the limits of our ability to lift Ashley at 65 pounds. Therefore, an additional 50 pounds would make all the difference in our capacity to move her. Furthermore, other than her Mom and Dad the only additional care givers entrusted to Ashley's care are her two Grandmothers, who find Ashley's weight even more difficult to manage. We tried hard and found it impossible to find qualified, trustworthy, and affordable care providers.

The main benefit of the height and weight reduction is that Ashley can be moved considerably more often, which is extremely beneficial to her health and well being. Currently, one person can carry Ashley, versus requiring two people or a hoisting harness and ropes, should she have grown larger. As a result, Ashley can continue to delight in being held in our arms and will be moved and taken on trips more frequently and will



have more exposure to activities and social gatherings (for example, in the family room, backyard, swing, walks, bathtub, etc.) instead of lying down in her bed staring at TV (or the ceiling) all day long. In addition, the increase in Ashley's movement results in better blood circulation, GI functioning (including digestion, passing gas), stretching, and motion of her joints.

Furthermore, Ashley remaining child sized has other practical ramifications such as:

- 1- She will continue to fit in and be bathed in a standard size bathtub. Since Ashley can't sit, she needs to lie down in the bathtub. Without the treatment eventually she would stop fitting in a standard size bathtub and would need a different arrangement for bathing.
- 2- Ashley is more comfortable lying down and does not like to sit in her wheelchair, she fusses and cries if she is in it for more than a short time. We move her around the house while lying down in a regular double-stroller (we face the chairs together, cover them with a thick double natural sheepskin and set the back of one to a reclining angle). The system works remarkably well; however, Ashley is already at the weight limit for which this stroller is designed (two babies).

Recently, a doctor suggested that Ashley will be less prone to infections as a result of her smaller size. Bedridden individuals are more susceptible to potentially fatal infections. Both the reduction in size in itself, and the increased movement and resulting blood circulation are expected to reduce the occurrence and magnitude of such infections including:

- 1- **Skin sores:** larger body weight leads to pressure skin ulceration or bed sores, providing an inlet for deadly bacterial infections (another way to look at this is that adults are more susceptible to bed sores than children).
- 2- **Pneumonia:** increased body weight increases the pressure on the chest and reduces the lungs' ability to expand, causing fluid build up in the lungs that increases the chance for pneumonia and breathing complications.
- 3- **Bladder infection:** similarly, increased body weight causes increased pressure on the bladder outlet, resulting in urinary retention and an increased risk for bladder infections.

These points make intuitive sense and so we decided to mention them; however, at this point we do not know of a study to reference that provides us with an objective and quantitative understanding of these benefits.

Avoiding Menstrual Discomfort through a Hysterectomy

Ashley has no need for her uterus since she will not be bearing children. This procedure will avoid the menstrual cycle and all the bleeding/discomfort/pain/cramps that are so commonly associated with it.

The procedure involved removing Ashley's uterus but keeping her ovaries to maintain her natural hormones.

Additional and incidental benefits include avoiding any possibility of pregnancy, which to our astonishment does occur to disabled women who are abused. The hysterectomy also eliminates the possibility of uterine cancer and other common and often painful complications that cause women later in life to undergo the procedure.

Preventing Breast Growth by Removing the Early Breast Buds

Ashley has no need for developed breasts since she will not breast feed and their presence would only be a source of discomfort to her. This is especially true since Ashley is likely destined to have large breasts, given her maternal and paternal female lineage; for example, an aunt had a breast reduction operation at age 19. Large breasts are uncomfortable lying down with a bra and even less comfortable without a bra. Furthermore, breasts impede securing Ashley in her wheelchair, stander, or bath chair, where straps across her chest are needed to support her body weight. Before the surgery Ashley had already exhibited sensitivity in her breasts.

Though this step in the treatment might seem extreme to some, it is a simple procedure when the breasts are still undeveloped. This operation involved removing Ashley's subcutaneous, almond-sized breast buds, which contain the milk glands, while keeping the areolas and nipples intact. This surgery was done with small incisions below the areola, the slight scars almost disappeared a month after the surgery. This operation is akin to removing a birthmark and is a very different surgery from a mastectomy on an adult woman with developed breasts. Furthermore, when done in conjunction with the hysterectomy this step poses little to no additional recovery time or surgery risk (for example, anesthesia is done once).

The breast bud removal has other benefits:

- 1- Avoiding the possibility of painful fibrocystic growth and future related surgeries. Women in Ashley's lineage have a history of fibrocystic growth.
- 2- Avoiding the possibility of breast cancer. Ashley has breast cancer history in her family.
- 3- Large breasts could "sexualize" Ashley towards her caregiver, especially when they are touched while she is being moved or handled, inviting the possibility of abuse.

Of all the things we wanted to do to provide lasting physical comfort and quality of life to Ashley, the breast bud removal posed the biggest challenge to Ashley's doctors, and to the ethics committee. We overcame this reluctance by detailing the benefits above, recounting Ashley's family history of breast problems, and pointing out the fact that the same procedure is commonly provided to males for cosmetic reasons and to mitigate unwanted breast development (Gynecomastia). In boys who might receive high-dose estrogen therapy in the future, breast growth will become an important consideration, and can be dealt with as in Ashley's case.

Addressing some Common Misconceptions

From observing early media coverage and visiting certain online discussion groups, it became clear to us that there are several misconceptions or misunderstandings about the treatment that we provided for our daughter and our motivation for pursuing it, which we address here.

We are thankful to the support and prayers from many, and we included some of the supportive comments below. At the same time we're surprised at the volume and magnitude of the critical comments. We carefully reviewed these comments: they seemed to us to be gut reactions without depth or rational consideration of the situation, the treatment, or the motivation behind it, which we hope this article sheds more light on. It seems that people are thinking of a child who is mostly normal or who might progress to approach normal. As we stated earlier, Ashley has not shown material progress in her mental ability since she was three months of age, she is dependent on us in every way (including position change), she can't hold a toy, and we're not sure she recognizes us.

To put our decision process in perspective, it is not uncommon for parents with children who have cancer or birth defects to pursue significantly more intrusive treatment (chemo or radiation therapy) or more involved surgery (limb amputations or face reconstruction), than what the “Ashley Treatment” entails. We strongly believe that the benefits that we’re seeking for Ashley are not any less worthy than these other unfortunate situations entail.

We hope that by now it is clear that the “Ashley Treatment” is about improving Ashley’s quality of life and not about convenience to her caregivers. **Ashley’s biggest challenge is discomfort and boredom and the “Ashley Treatment” goes straight to the heart of this challenge.** It is common for Ashley to be uncomfortable or to be bored. Even though Ashley’s level of tolerance has increased along the years, she is helpless when bothered and her only recourse is to cry until someone comes to her rescue. These episodes are triggered by something as simple as sliding off the pillow or a hair landing on her face and tickling/bothering her, let alone menstrual cramps, adult-level bed sores, and discomfort caused by large breasts. Also, without the treatment, Ashley could not be moved as frequently or be as included in family life, and we would not experience the joy of being an intact family as often.

If people have concerns about Ashley’s dignity, **she will retain more dignity in a body that is healthier, more of a comfort to her, and more suited to her state of development** as George Dvorsky, a member of the Board of Directors for the Institute for Ethics and Emerging Technologies, alludes to in a related article⁴: “If the concern has something to do with the girl’s dignity being violated, then I have to protest by arguing that the girl lacks the cognitive capacity to experience any sense of indignity. Nor do I believe this is somehow demeaning or undignified to humanity in general; the treatments will endow her with a body that more closely matches her cognitive state – both in terms of her physical size and bodily functioning. The estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby.”

Even though caring for Ashley involves hard and continual work, **she is a blessing and not a burden.** She brings a lot of love to our hearts as we’re sure all “Pillow Angels” bring their families. If there is a prize for those who have the record of how often they are told “I Love You”, we’re certain that these kids would win it effortlessly. Ashley’s presence in our home kindles abundant feelings of love in all members of the family. It is a joy just being with her, she brings nourishment to our souls; it is a pleasure to visit with her and sweet talk her and observe her innocent and genuine smile. Ashley sets the barometer in our home, when she is happy we’re happy and when she is not we’re not.

We are very fortunate that Ashley is a healthy child, outside her abnormal mental development, and is in a stable condition. We’re describing our unique experience which is not universal in this regard, and most likely not even representative. We fully understand that different “Pillow Angels” have different problems and pose different challenges to their caregivers, and that different families have different abilities and resources to provide for their special needs children.

The decision to move forward with this treatment, unlike what most have thought, was not difficult. Ever since we researched the idea and with Ashley's doctor's confirmation that it could be done, we focused squarely on getting it done as quickly as we could to maximize the benefits. It was clear to us that the lifelong benefits to Ashley by far outweigh risk factors associated with the treatment.

Furthermore, **we did not pursue this treatment with the intention of prolonging Ashley's care at home.** We would never turn the care of Ashley over to strangers even if she had grown tall and heavy. In the extreme, even an Ashley at 300 pounds, would still be at home and we would figure out a way to take care of her.

The objection that this treatment interferes with nature is one of the most ridiculous objections of all; medicine is all about interfering with nature. Why not let cancer spread and nature takes its course. Why give antibiotics for infections? Even an act as basic as cutting hair or trimming nails is interfering with nature.

Some question how God might view this treatment. **The God we know wants Ashley to have a good quality of life and wants her parents to be diligent about using every resource at their disposal** (including the brains that He endowed them with) **to maximize her quality of life.** Knowingly allowing avoidable suffering for a helpless and disabled child can't be a good thing in the eyes of God. Furthermore, the God we know wants us to actively share our experience and learning with the rest of the world to help all "Pillow Angels" and other special need children in reaping the benefits of the "Ashley Treatment".

We want to avoid sensationalism or philosophical debates about what we did and why we did it. We'd rather care for and enjoy Ashley than get into endless debates. In our opinion, only parents with special-needs children are in a position to fully relate to this topic. Unless you are living the experience, you are speculating and you have no clue what it is like to be the bedridden child or their caregivers. Furthermore, in the case of the female aspects of the treatment, women are in a better position to relate to these aspects and the benefits for which they are intended.

What this Means to Other Families with "Pillow Angels"

There are hundreds of postings in dozens of blogs by parents with special need children, indicating that they wish they had the option of the "Ashley Treatment" before their kids reached their adult size and how this would have changed their lives significantly. You can see a sampling of these points of view in [the testimonies section](#). One mother explained in graphic detail how heart breaking it was for her to have to let her daughter go to a care center since "I am tired, my body is breaking down rapidly, and emotionally drained" and she stopped being able to care for her daughter at home. It is this type of family that we hope our experience will help some day.

Clearly, the "Ashley Treatment" is not for all disabled kids. Our daughter's condition pointed to a clear decision where the benefits far outweigh the risks and short term discomfort associated with surgery. Families of other kids may likewise find the "Ashley

Treatment” to be the right approach for them. It is our hope that this treatment becomes well-accepted and available to such families, so they can bring its benefits to their special needs child if appropriate and at an optimal age in order to obtain the most benefits.

Clearly, a decision on the applicability of the “Ashley Treatment” needs to be made upon careful evaluation of their child’s unique condition, with help from their doctors, and careful evaluation of the benefits that might be obtained. We believe the parents are in the best position to make this evaluation and ultimately make this decision.

In addition, our understanding is that the growth limiting aspect of the “Ashley Treatment” is applicable to male children. It seems to us that it even makes more sense in their case, since boys tend to grow taller and bigger. In boys hysterectomy will not be an issue; however, since estrogen will result in breast growth, the breast bud removal surgery would still need to be considered.

Acknowledgment

Our sincerest thanks to Ashley’s doctors and the surgery team at Seattle Children’s for their world class expertise, competence and support throughout this pioneering treatment. Special thanks to Doctor Daniel F. Gunther, without whose courage, confidence, knowledge, open mindedness and unwavering support the treatment would not have been realized and the idea would have remained just an idea. We know that many endocrinologists would not have ventured into such new territory. It is our, and Ashley’s luck, that we knocked the right door.

We thank our good friend Margaret Russell for her tireless support in reviewing and editing many versions of this article, which helped clarify its message significantly. We thank our family and friends for their love and support throughout the Ashley journey including her treatment.

References

- [1] “Attenuating Growth in Children with Profound Developmental Disability, A New Approach to an Old Dilemma”, Archives of Pediatrics & Adolescent Medicine, Vol. 160, No. 10, October 2006, Daniel F. Gunther, MD, MA; Douglas S. Diekema, MD, MPH.
- [2] This story topped the Health section of Google News between January 5th and January 8th – there have been more than 400 articles worldwide.
- [3] “Pillow Angel Parents Deserve Credit, Not Blame”, BLOG: SCIAM OBSERVATIONS, Opinions, arguments and analyses from the editors of Scientific American, January 4th, 2007.
- [4] “Helping families care for the helpless”, George Dvorsky, Sentient Developments, Institute for Ethics and Emerging Technologies, November 6th, 2006.

Exhibit C

**Letter from David Carlson, Associate Director of Legal
Advocacy, WPAS, to Lisa Brandenburg, Interim Executive
Director, UWMC (January 8, 2007)**

WASHINGTON PROTECTION & ADVOCACY SYSTEM

315 Fifth Ave. S., Suite 850
Seattle, WA 98104
(206) 324-1521
(800) 562-2702
(206) 957-0728 TTY
(800) 905-0209 TTY
(206) 957-0729 Fax
www.wpas-rights.org

January 8, 2007

Via Facsimile and First Class Mail

Lisa Brandenburg
Interim Executive Director
University of Washington Medical Center
1959 N.E. Pacific
Seattle, WA 98195

Re: **Washington Protection & Advocacy System Investigation of University of
Washington Medical Center's Policies for Growth Attenuation Treatment**

Dear Ms. Brandenburg:

The Washington Protection & Advocacy System ("WPAS") is a private non-profit advocacy agency that is federally mandated to provide protection and advocacy services to individuals with disabilities in the state of Washington pursuant to the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 10541, *et seq.*, the Protection and Advocacy for Individuals with Mental Illnesses Act, 42 U.S.C. § 10801, *et seq.*, the Protection and Advocacy for Individual Rights Act, 29 U.S.C. § 794e, and the regulations promulgated thereto, as well as RCW 71A.10.080. As you may not be familiar with WPAS or our federally mandated authority, I am providing you with a brief description of our authority and am enclosing copies of the relevant federal laws and regulations for your convenience.

Under the DD, PAIMI, and PAIR Acts, a primary component of WPAS's mandate is to conduct a "full investigation" when WPAS has probable cause to believe that an individual or a group of individuals with disabilities have been or may be abused and/or neglected. *See* 45 CFR §1386.19.

The PADD Act regulations define "probable cause" as "a reasonable ground for belief that an individual with developmental disabilities has been, or may be subject to abuse or neglect. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse and neglect." 45 C.F.R. §1386.19. Further, courts have specifically held that a protection and advocacy system is the final arbiter of probable cause. *Arizona Center for Disability Law v. Allen*, 197 F.R.D. 689, 693 (D. Az. 2000).

Pursuant to its federal mandate under the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041, *et seq.* and its implementing regulations, WPAS is investigating potential abuse and neglect resulting from policies and practices associated with "Growth

Lisa Brandenburg
January 8, 2007
Page 2

Attention” treatment provided to people with developmental disabilities (also referred to as the “Ashley’s Treatment”).

It is the understanding of WPAS that Growth Attenuation treatment involves sterilization of children with cognitive disabilities. As I am sure you aware, there are specific legal procedures that must be followed, as required by Washington state law, before a person lacking capacity to provide informed consent may be sterilized. *See In re Hayes*, 93 Wn.2d 228 (1980); *In re K.M.*, 62 Wn.App. 811 (1991). Pursuant to its probable cause authority under the PADD Act, WPAS is investigating the policies and procedures the University of Washington Medical Center (“UWMC”) uses in the provision of Growth Attenuation treatment to people with developmental disabilities. To conduct this investigation, it is necessary UWMC provide WPAS the following information:

- 1) The number of people with developmental disabilities who have received or are scheduled to receive any procedure that is considered or could be considered part of the Growth Attenuation treatment;
- 2) All documents describing the process utilized by any treating professional considering authorization of any form of Growth Attenuation treatment for people with developmental disabilities;
- 3) All documents describing the process utilized by any ethics committee considering authorization of any form of Growth Attenuation treatment for people with developmental disabilities;
- 4) All policies governing procedures resulting in the sterilization of people who lack capacity to provided informed consent; and
- 5) All court orders obtained granting UWMC and/or its treating professionals the authority to sterilize people who lack capacity to provided informed consent.

Pursuant to federal statute, WPAS must be provided access to the requested information within three business days. 42 U.S.C. § 15043 (a)(2)(J)(i). I look forward to your prompt response to this request. If you have any questions, please feel free to contact me at (206) 324-1521, ext. 240. Thank you.

Sincerely,



David Carlson
Associate Director of Legal Advocacy

cc: Dina Yunker-AAG

Exhibit D

**Letter from David Carlson, Associate Director of Legal
Advocacy, WPAS, to Jodi Long, Associate General Counsel,
Children's Hospital (January 10, 2007)**

WASHINGTON PROTECTION & ADVOCACY SYSTEM

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(800) 905-0209 TTY
(206) 957-0729 Fax
www.wpas-rights.org

January 10, 2007

Via Facsimile and First Class Mail

Jodi Long
Associate General Counsel
Children's Hospital and Regional Medical Center
P.O. Box 5371
Seattle, WA 98105-0371

Re: **Washington Protection & Advocacy System Investigation of Children's Hospital's
Policies for the "Ashley Treatment"**

Dear Ms. Long:

The Washington Protection & Advocacy System ("WPAS") is a private non-profit advocacy agency that is federally mandated to provide protection and advocacy services to individuals with disabilities in the state of Washington pursuant to the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 10541, *et seq.*, the Protection and Advocacy for Individuals with Mental Illnesses Act, 42 U.S.C. § 10801, *et seq.*, the Protection and Advocacy for Individual Rights Act, 29 U.S.C. § 794e, and the regulations promulgated thereto, as well as RCW 71A.10.080. As you may not be familiar with WPAS or our federally mandated authority, I am providing you with a brief description of our authority and am enclosing copies of the relevant federal laws and regulations for your convenience.

Under the DD, PAIMI, and PAIR Acts, a primary component of WPAS's mandate is to conduct a "full investigation" when WPAS has probable cause to believe that an individual or a group of individuals with disabilities have been or may be abused and/or neglected. *See* 45 CFR §1386.19.

The PADD Act regulations define "probable cause" as "a reasonable ground for belief that an individual with developmental disabilities has been, or may be subject to abuse or neglect. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse and neglect." 45 C.F.R. §1386.19. Further, courts have specifically held that a protection and advocacy system is the final arbiter of probable cause. *Arizona Center for Disability Law v. Allen*, 197 F.R.D. 689, 693 (D. Az. 2000).

Pursuant to its federal mandate under the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041, *et seq.* and its implementing regulations, WPAS is investigating potential abuse and neglect resulting from policies and practices associated with the "Ashley Treatment" provided to people with developmental disabilities.

It is the understanding of WPAS that the Ashley Treatment involves sterilization, breast bud removal, and growth attenuation treatments for children with cognitive disabilities. As I am sure you are aware, there are specific legal procedures that must be followed, as required by Washington state law, before a person lacking capacity to provide informed consent may be sterilized. *See In re Hayes*, 93 Wn.2d 228 (1980); *In re K.M.*, 62 WnApp 811 (1991). Pursuant to its probable cause authority under the PADD Act, WPAS is investigating the policies and procedures that Children's Hospital and Regional Medical Center (hereinafter "Children's Hospital") uses in the provision of the Ashley Treatment to people with developmental disabilities. To conduct this investigation, it is necessary for Children's Hospital to provide WPAS the following information:

- 1) The number of people with developmental disabilities who have received or are scheduled to receive any procedure that is considered or could be considered part of the Ashley Treatment;
- 2) All documents describing the process utilized by any treating professional considering authorization of any portion of the Ashley Treatment for people with developmental disabilities;
- 3) All documents describing the process utilized by any ethics committee considering authorization of any portion of the Ashley Treatment for people with developmental disabilities;
- 4) All policies governing procedures resulting in the sterilization of people who lack capacity to provide informed consent; and
- 5) All court orders obtained granting Children's Hospital and/or its treating professionals the authority to sterilize people who lack capacity to provide informed consent.

Pursuant to federal statute, WPAS must be provided access to the requested information within three business days. 42 U.S.C. § 15043 (a)(2)(J)(i). I look forward to your prompt response to this request. If you have any questions, please feel free to contact me at (206) 324-1521, ext. 240. Thank you.

Sincerely,



David Carlson
Associate Director of Legal Advocacy

UNITED STATES CODE ANNOTATED
TITLE 42. THE PUBLIC HEALTH AND WELFARE
CHAPTER 144--DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS
SUBCHAPTER I--PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES
PART C--PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

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Current through P.L. 108-10, approved 03-11-03

§ 15043. System required

(a) System required

In order for a State to receive an allotment under part B of this subchapter or this part--

(1) the State shall have in effect a system to protect and advocate the rights of individuals with developmental disabilities;

(2) such system shall--

(A) have the authority to--

(i) pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements, with particular attention to members of ethnic and racial minority groups; and

(ii) provide information on and referral to programs and services addressing the needs of individuals with developmental disabilities;

(B) have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred;

(C) on an annual basis, develop, submit to the Secretary, and take action with regard to goals (each of which is related to 1 or more areas of emphasis) and priorities, developed through data driven strategic planning, for the system's activities;

(D) on an annual basis, provide to the public, including individuals with developmental disabilities attributable to either physical impairment, mental impairment, or a combination of physical and mental impairment, and their representatives, and as appropriate, non-State agency representatives of the State Councils on Developmental Disabilities, and Centers, in the State, an opportunity to comment on--

(i) the goals and priorities established by the system and the rationale for the establishment of such goals; and

(ii) the activities of the system, including the coordination of services with the entities carrying out advocacy programs under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the Older Americans

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Act of 1965 (42 U.S.C. 3001 et seq.), and the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (42 U.S.C. 10801 et seq.), and with entities carrying out other related programs, including the parent training and information centers funded under the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), and activities authorized under section 3011 or 3012 of Title 29;

(E) establish a grievance procedure for clients or prospective clients of the system to ensure that individuals with developmental disabilities have full access to services of the system;

(F) not be administered by the State Council on Developmental Disabilities;

(G) be independent of any agency that provides treatment, services, or habilitation to individuals with developmental disabilities;

(H) have access at reasonable times to any individual with a developmental disability in a location in which services, supports, and other assistance are provided to such an individual, in order to carry out the purpose of this part;

(I) have access to all records of--

(i) any individual with a developmental disability who is a client of the system if such individual, or the legal guardian, conservator, or other legal representative of such individual, has authorized the system to have such access;

(ii) any individual with a developmental disability, in a situation in which--

(I) the individual, by reason of such individual's mental or physical condition, is unable to authorize the system to have such access;

(II) the individual does not have a legal guardian, conservator, or other legal representative, or the legal guardian of the individual is the State; and

(III) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect; and

(iii) any individual with a developmental disability, in a situation in which--

(I) the individual has a legal guardian, conservator, or other legal representative;

(II) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect;

(III) such representative has been contacted by such system, upon receipt of the name and address of such representative;

(IV) such system has offered assistance to such representative to resolve the situation; and

(V) such representative has failed or refused to act on behalf of the individual;

(J)(i) have access to the records of individuals described in subparagraphs (B) and (I), and other records that are relevant to conducting an investigation, under the circumstances described in those subparagraphs, not later than 3 business days after the system makes a written request for the records involved; and

(ii) have immediate access, not later than 24 hours after the system makes such a request, to the records without consent from another party, in a situation in which services, supports, and other assistance are provided to an individual with a developmental disability--

(I) if the system determines there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy; or

(II) in any case of death of an individual with a developmental disability;

(K) hire and maintain sufficient numbers and types of staff (qualified by training and experience) to carry out such system's functions, except that the State involved shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the system, to the extent that such policies would impact the staff or functions of the system funded with Federal funds or would prevent the system from carrying out the functions of the system under this part;

(L) have the authority to educate policymakers; and

(M) provide assurances to the Secretary that funds allotted to the State under section 15042 of this title will be used to supplement, and not supplant, the non-Federal funds that would otherwise be made available for the purposes for which the allotted funds are provided;

(3) to the extent that information is available, the State shall provide to the system--

(A) a copy of each independent review, pursuant to section 1396a(a)(30)(C) of this title, of an Intermediate Care Facility (Mental Retardation) within the State, not later than 30 days after the availability of such a review; and

(B) information about the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1396n(c) of this title) receive; and

(4) The agency implementing the system shall not be redesignated unless--

(A) there is good cause for the redesignation;

(B) the State has given the agency notice of the intention to make such redesignation, including notice regarding the good cause for such redesignation, and given the agency an opportunity to respond to the assertion that good cause has been shown;

(C) the State has given timely notice and an opportunity for public comment in an accessible format to individuals with developmental disabilities or their representatives; and

(D) the system has an opportunity to appeal the redesignation to the Secretary, on the basis that the redesignation was not for good cause.

(b) American Indian consortium

Upon application to the Secretary, an American Indian consortium established to provide protection and advocacy services under this part, shall receive funding pursuant to section 15042(a)(6) of this title to provide the services. Such consortium shall be considered to be a system for purposes of this part and shall coordinate the services with other systems serving the same geographic area. The tribal council that designates the consortium

42 USCA § 15043
42 U.S.C.A. § 15043

Page 4

shall carry out the responsibilities and exercise the authorities specified for a State in this part, with regard to the consortium.

(c) Record

In this section, the term "record" includes--

(1) a report prepared or received by any staff at any location at which services, supports, or other assistance is provided to individuals with developmental disabilities;

(2) a report prepared by an agency or staff person charged with investigating reports of incidents of abuse or neglect, injury, or death occurring at such location, that describes such incidents and the steps taken to investigate such incidents; and

(3) a discharge planning record.

CREDIT(S)
2003 Electronic Update

(Pub.L. 106-402, Title I, § 143, Oct. 30, 2000, 114 Stat. 1714.)

42 U.S.C.A. § 15043

42 USCA § 15043

END OF DOCUMENT

45 CFR § 1386.19
45 C.F.R. § 1386.19

Page 1

CODE OF FEDERAL REGULATIONS
TITLE 45--PUBLIC WELFARE
SUBTITLE B--REGULATIONS RELATING
TO PUBLIC WELFARE
CHAPTER XIII--OFFICE OF HUMAN
DEVELOPMENT SERVICES, DEPARTMENT
OF HEALTH AND
HUMAN SERVICES
SUBCHAPTER I--THE ADMINISTRATION
ON DEVELOPMENTAL DISABILITIES,
DEVELOPMENTAL DISABILITIES
PROGRAM
PART 1386--FORMULA GRANT PROGRAMS
SUBPART B--STATE SYSTEM FOR
PROTECTION AND ADVOCACY OF THE
RIGHTS OF
INDIVIDUALS WITH DEVELOPMENTAL
DISABILITIES

Current through March 25, 2003; 68 FR 14521

§ 1386.19 Definitions.

As used in §§ 1386.20, 1386.21, 1386.22 and 1386.25 of this part the following definitions apply:

Abuse means any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes such acts as: Verbal, nonverbal, mental and emotional harassment; rape or sexual assault; striking; the use of excessive force when placing such an individual in bodily restraints; the use of bodily or chemical restraints which is not in compliance with Federal and State laws and regulations or any other practice which is likely to cause immediate physical or psychological harm or result in long term harm if such practices continue.

Complaint includes, but is not limited to any report or communication, whether formal or informal, written or oral, received by the system including media accounts, newspaper articles, telephone calls (including anonymous calls), from any source alleging abuse or neglect of an individual with a developmental disability.

Designating Official means the Governor or other State official, who is empowered by the Governor or State legislature to designate the State official or

public or private agency to be accountable for the proper use of funds by and conduct of the State Protection and Advocacy agency.

Facility includes any setting that provides care, treatment, services and habilitation, even if only "as needed" or under a contractual arrangement. Facilities include, but are not limited to the following:

Community living arrangements (e.g., group homes, board and care homes, individual residences and apartments), day programs, juvenile detention centers, hospitals, nursing homes, homeless shelters, jails and prisons.

Full Investigation means access to facilities, clients and records authorized under these regulations, that is necessary for a protection and advocacy (P&A) system to make a determination about whether alleged or suspected instances of abuse and neglect are taking place or have taken place. Full investigations may be conducted independently or in cooperation with other agencies authorized to conduct similar investigations.

Legal Guardian, conservator and legal representative all mean an individual appointed and regularly reviewed by a State court or agency empowered under State law to appoint and review such officers and having authority to make all decisions on behalf of individuals with developmental disabilities. It does not include persons acting only as a representative payee, person acting only to handle financial payments, attorneys or other persons acting on behalf of an individual with developmental disabilities only in individual legal matters, or officials responsible for the provision of treatment or habilitation services to an individual with developmental disabilities or their designees.

Neglect means a negligent act or omission by an individual responsible for providing treatment or habilitation services which caused or may have caused injury or death to an individual with developmental disabilities or which placed an individual with developmental disabilities at risk of injury or death, and includes acts or omissions such as failure to: establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care to an individual

45 CFR § 1386.19
45 C.F.R. § 1386.19

Page 2

with developmental disabilities; provide a safe environment which also includes failure to maintain adequate numbers of trained staff.

Probable cause means a reasonable ground for belief that an individual with developmental disabilities has been, or may be, subject to abuse or neglect. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse or neglect.

[61 FR 51155, Sept. 30, 1996]

<General Materials (GM) - References,
Annotations, or Tables>

45 C. F. R. § 1386.19

45 CFR § 1386.19

END OF DOCUMENT

Exhibit E

**Persons Not Capable of Providing Informed Consent, UW
Medicine Informed Consent Manual (2001-2004)**

UW Medicine

Informed Consent Manual

2001-2004

Consent Manual



Persons Not Capable of Providing Informed Consent

Legally Authorized Surrogate Decision Makers.

Where medical treatment is required for an adult patient who is unable to give informed consent, Washington law ([RCW 7.70.065\(1\)](#)) establishes who may give consent on the patient's behalf in the following order of priority:

1. The patient's legal guardian, if the guardian has the power to make health care decisions on behalf of the patient.
2. The individual, if any, to whom the patient has given a durable power of attorney that encompasses the authority to make health care decisions.
3. The patient's spouse.
4. All the children of the patient who are at least eighteen (18) years of age.
5. The parents of the patient.
6. All the adult brothers and sisters of the patient.

It is important to note that legally authorized surrogates are unable to consent to certain specific types of treatment. (See [Limitations](#).)

The Physician / Practitioner seeking informed consent must make reasonable efforts to locate and secure authorization from a competent person in the first or succeeding class. If no such person is available, authorization may be given by a person or persons in the next class in the order of descending priority. However, a person in a lower class may not provide consent if a person in a higher class has refused to give such authorization. **Further, if there are two or more individuals in the same class, the decision must be unanimous among all available members of that class.** ([RCW 7.70.065\(2\)](#))

Before the person authorized to provide informed consent exercises that authority, he/she must determine in good faith that the patient, if competent, would consent to the proposed health care. If such a determination cannot be made, the decision to consent to the proposed health care may be made only after determining that the proposed health care is in the patient's best interests. ([RCW 7.70.065\(3\)](#)). A patient care conference with the class of individuals who cannot agree is recommended as a way to resolve disputes.

If no person as designated above is available, or the persons in the same class cannot agree, then unless there is an emergency, the provision of care should be deferred. If there is not a [surrogate decision](#)

maker and the care does not meet our definition of an emergency, then the situation may be reviewed with the Attorney General's Office, UW Division's Health Sciences Office (206-543-9220) for consideration of a guardianship proceeding.

Conflict Resolution. One mechanism for addressing conflict is through a patient care conference with the following participants:

- Members of the specific class of legally authorized surrogate decision maker(s)
- Attending and consulting physicians
- Nursing representative(s)
- Social worker

Guidelines for the patient care conference:

A. When the patient is competent, the patient's wishes must generally be followed

B. When the patient is incompetent, the patient's legally authorized surrogate decision maker(s) may make decisions regarding the patient's care and provide informed consent for that care.

C. Physicians should discuss with the participants:

1. The patient's condition
2. Specific diagnosis
3. Response to therapy
4. Prognosis
5. The patient's capacity to make decisions.

D. Goals of therapy and specific treatment options, including non-treatment, should then be discussed. The informed consent discussion should include all the elements of informed consent.

E. A course of action may be identified and communicated to conference participants.

F. Details of the patient care conference and outcome should be documented in the patient's medical record, including a list of those persons present at the conference.

Standards for Surrogate Decision-Making

A legally authorized surrogate decision-maker must make a decision based on the doctrine of substituted judgment. The substituted judgment standard requires the surrogate decision-maker to determine whether the patient, if competent, would have consented to the proposed health care. The surrogate decision-maker must consider all relevant information that would influence the patient's decision. These include:

- Patient's prior statements regarding medical treatment;
- Patient's express wishes, even if made while incompetent;
- Patient's religious or moral views;
- Patient's prognosis in the absence of treatment;
- Patient's prognosis with the different treatment alternatives;
- The risk of adverse side effects;
- Intrusiveness or severity of the proposed treatment;
- Patient's ability to cooperate and assist with post-treatment therapy; and
- Wishes of family and friends, if those wishes would have impacted patient.

In some instances, a legally authorized surrogate decision-maker cannot in good faith determine whether the patient, if competent, would have consented to a particular course of treatment. In these situations the legally authorized surrogate must determine what is in the best interest of the patient. The best interest standard requires consideration of the following:

- Patient's present level of physical, sensory, emotional, and cognitive functioning;
- Various treatment options and the risks, side effects and benefits of each option;
- Life expectancy and prognosis for recovery with and without treatment
- Degree of pain from expected treatment or cessation of treatment;
- Degree of dependency and loss of dignity resulting from the medical condition or treatment.

Limitations on the Authority of Surrogate Decision Makers

Washington law limits the authority of legally authorized surrogates to consent to certain types of health care or procedures.

1. Sterilization of Mentally Incompetent Person. Legally authorized surrogates may not consent to the sterilization of a mentally incompetent person. Only the patient may provide informed consent for a medical procedure that would result in sterilization. If the patient cannot give informed consent, then a court order authorization must be obtained.

2. Limits on Guardianship. RCW 11.92.043(5) provides that guardians (and by analogy other legally authorized surrogates) may NOT consent to:

- a. Therapy or other procedure that induces convulsion

- b. Surgery solely for the purpose of psychosurgery
- c. Other psychiatric or mental health procedures that restrict physical freedom of movement, or the rights set forth in [RCW 71.05.370](#).

Specific court authorization is required under Washington law for these procedures ([RCW 11.92.043 \(5\)](#)). The intent of this limitation is to require court approval before a guardian or other legally authorized surrogate may consent to highly intrusive, irreversible medical treatment that may seriously affect the person's bodily integrity.

[Top](#)[Consent Manual](#) | [APOP](#) | [Infection Control](#) | [Medical Staff Bylaws](#) | [Medical Staff Manual](#)

Contact mrhodes@u.washington.edu for comments.

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Exhibit F

Letter from Jeffery Sconyers, General Counsel, Seattle Children's Hospital and Regional Medical Center to David Carlson, Associate Director of Legal Advocacy, Washington Protection and Advocacy System (January 22, 2007)

January 22, 2007

Hand Delivered

David Carlson
Associate Director of Legal Advocacy
Washington Protection & Advocacy System
315 – 5th Avenue South, Suite 850
Seattle, Washington 09104

Re: **WPAS Request for Documents**

Dear Mr. Carlson:

I am writing you on behalf of Children's Hospital and Regional Medical Center in response to your letter dated January 10, 2007, in which you ask that we provide WPAS with information relating to the policies and procedures Children's uses in the provision of sterilization, breast bud removal, and high dose estrogen treatment for purposes of growth attenuation for developmentally disabled children (for purposes of your letter and this response, the "Ashley Treatment"). We understand the relevant time frame for your requests to be from July 28, 2004 until the present. Your requests and our responses follow.

1. The number of people with developmental disabilities who have received or are scheduled to receive any procedure that is considered or could be considered part of the Ashley Treatment.

Only one patient has received the "Ashley Treatment," and no additional patients are scheduled to do so. Three patients have undergone partial or full hysterectomies, as clinically appropriate treatment for congenital defects of the uterus (2 cases) and uncontrollable uterine bleeding (1 case). One male patient underwent a single mastectomy for prominent male gynecomastia. None of these patients was developmentally disabled.

We are confident that we have identified all patients in whom uterine removal or breast removal have been undertaken. Such cases require OR scheduling or inpatient care making identification relatively easy. High dose estrogen therapy requires only a prescription and most often occurs in the ambulatory setting, either in a private office or at one of our clinics. We have yet to determine whether other patients with developmental disabilities have been prescribed high dose estrogen for purposes of growth attenuation. We do know that if any such patients exist, they have not also received surgery for either a hysterectomy or breast bud removal. Because high dose

estrogen therapy prescriptions may be filled in any community pharmacy, Children's Hospital does not have clinical records that document this treatment. There are also many additional clinical indications for high dose estrogen therapy, beyond its use for growth attenuation. Our only option for gathering such information would be to survey our medical staff asking them to volunteer if they have utilized this therapy, the indications for the therapy and whether the children for whom it was prescribed were disabled. We are concerned that we could not assure the accuracy or completeness of such responses. We would like to discuss with you whether and how to proceed with such a survey, including the desired results of doing so.

2. All documents describing the process utilized by any treating professional considering authorization of any portion of the Ashley Treatment for people with developmental disabilities.

The charter for Children's Growth Attenuation/Sterilization Review Subcommittee is attached as Exhibit 1. This multidisciplinary subcommittee, created in April of 2005, will review and make recommendations to Children's Medical Director when families or their providers are considering growth attenuation therapy, breast bud removal, or sterilization for developmentally disabled patients.

3. All documents describing the process utilized by any ethics committee considering authorization for any portion of the Ashley Treatment for people with developmental disabilities.

The mission statement for Children's Ethics Committee is attached as Exhibit 2. The Ethics Committee is a multidisciplinary group of providers and community members with training in medical ethics who provide consultation at the request of patients, families or practitioners who are facing complicated and ethically challenging questions regarding medical care. As with all medical consultations, its recommendations are not binding.

4. All policies governing procedures resulting in the sterilization of people who lack capacity to provide informed consent.

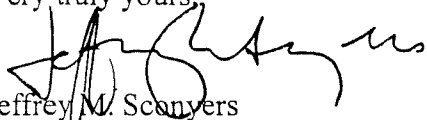
Children's policy governing informed consent is attached as Exhibit 3. It does not specifically address sterilization of patients who lack capacity to give informed consent, and we have found no other policy that does.

5. All court orders obtained granting Children's Hospital and/or its treating professionals the authority to sterilize people who lack capacity to provide informed consent.

We have not located any such court order.

We trust that you will find our materials responsive to your requests. As we have reviewed our policies and procedures in connection with your investigation, we have identified opportunities to improve the processes we have in place to protect the rights of our disabled patients. We look forward to collaborating with you as we do so.

Very truly yours,



Jeffrey M. Sconyers
Vice President and General Counsel

C: Thomas N. Hansen, M.D., Chief Executive Officer
Pat Hagan, President and Chief Operating Officer

Attachments 1 – 3

Exhibit G

**Children's Hospital and Regional Medical Center Growth
Attenuation/Sterilization Review Subcommittee**

Children's Hospital & Regional Medical Center
Growth Attenuation/Sterilization Review Subcommittee

I. Purpose

The Growth Attenuation/Sterilization Review Subcommittee is established as an ad hoc subcommittee of the Quality Improvement Steering Committee to provide consultative assistance to providers and families with children for whom chemical treatments to limit growth, procedures to limit or eliminate breast development, permanent reproductive sterilization procedures, or a combination of some or all of these therapies are being considered; to provide direction to the hospital on the medical and ethical appropriateness of children at Children's who are under consideration as candidates for chemical growth attenuation, permanent sterilization, breast bud removal, or a combination of such therapies.

II. Scope and Activities

This subcommittee, through its familiarity with State law, the natural history of children with severe disabilities, the risk factors facing these children after puberty, as well as the chemical and surgical options available to families, will serve as an educational resource for the care team and families served at Children's. Armed with this knowledge and expertise the Subcommittee will review all cases under consideration at Children's for therapeutic interventions and make recommendations for care to the Children's Vice President and Medical Director.

All patients suggested for therapy by the Subcommittee and approved by the Medical Director will be reviewed with the VP, General Counsel and President and CEO before final written approval is provided to the child's care team and family.

The Subcommittee is a subcommittee of the Quality Improvement Steering Committee, and functions as part of the Hospital's coordinated quality improvement program. All meetings, minutes, deliberations, records and proceedings of the Subcommittee shall be confidential and protected from disclosure as provided in RCW 70.41.200

II. Composition

The Committee will consist of members appointed by the Medical Director and representing the following disciplines:

- Medical Ethics / Ethics Committee
- Endocrinology
- Adolescent Medicine
- Neurodevelopmental / Special Needs

- Social Work
- Child Psychiatry / Behavioral Health
- Nursing Service
- Department of Surgery
- Medical Administration

Members will serve three year terms and may be reappointed for a second three year term. The Committee Chair will be appointed by the VP Medical Director and will serve in that capacity for one three year term.

EX OFFICIO

The VP General Counsel, VP Medical Director and Nurse Executive

III. Meetings

The Committee will meet at least twice a year to conduct routine business. The Committee will also meet at the call of the Chair of the Committee to discuss specific cases under consideration at Children's for care. Meeting agendas will be prepared and provided in advance to members, along with appropriate briefing materials. Minutes will be prepared. Periodic reports to the QISC will be made on significant activities.

Approved:

Revised:

Exhibit H

**The Mission Statement for the Ethics Committee of the
Children's Hospital & Regional Medical Center**

**THE MISSION STATEMENT FOR THE ETHICS COMMITTEE
OF THE CHILDREN'S HOSPITAL & REGIONAL MEDICAL CENTER**

The Ethics Committee of the Children's Hospital & Regional Medical Center is an interdisciplinary hospital committee consisting of a chairman, appointed by the Medical Director. The membership is representative of the medical staff, other hospital health care providers, the Board of Trustees, and the community. Membership shall serve on a continuous basis subject to annual review and reappointment by the Medical Director and Chairman.

The mission of the Ethics Committee shall be consistent with the overall mission statement of Children's Hospital and Medical Center. The Ethics Committee serves to educate both health care staff and the larger community (where appropriate) about bioethics issues, to assist in policy development on bioethics issues, and to assist patients, their families, and health care providers when they are confronted with complicated/ill-defined/morally difficult decisions regarding medical care.

Specifically, the Committee shall:

- serve as a resource on ethical issues
- develop education and other programs on ethics-related issues
- review and make recommendations on ethics-related policies and procedures; these recommendations would be directed to the Medical Director for his/her consideration
- conduct formal review of specific patient-related ethical issues and provide for prompt/timely consultation at the request of family members and/or health care providers (the latter is accomplished by the committee sponsored ethics consultation service)
- make such rules and develop such procedures as may be appropriate for the Committee to function effectively

Exhibit I

**Legally Authorized Person for Informed Consent Decision
Making When a Patient is a Minor**

Legally Authorized Person for Informed Consent Decision Making When a Patient is a Minor

POLICY: Children's looks to the legally authorized person for informed consent decision-making. Washington State law requires that person to act in good faith to represent the best interests of the patient and to consent on behalf of a minor patient only when the proposed therapy is in the patient's best interests.

PROCEDURE:

I. Statutory Priority of Surrogate Decision makers

Washington State law authorizes informed consent for a patient in the following (descending) order:

- A. Appointed guardian of the patient
- B. Individual to whom the (adult) patient has given a durable Power of Attorney including the authority to make health care decisions
- C. Spouse of the patient
- D. Adult children of the patient
- E. Parents of the patient
- F. Adult brothers and sisters of the patient

If the physician is unable to locate a competent person in the first or succeeding class, any person in the next class may give authorization. No person may provide informed consent if a person of higher priority refused to give informed consent or if the decision was not unanimous among all available members in a class. For "parents of the patient", other law may also apply.

If you are dealing with a situation where there is no one that fits the roles identified in items A-F, please contact Risk Management (David Stallings x75165) or legal counsel (Jodi Long at x75243 or Jeff Sconyers at x72044).

II. Decision Making Flow Sheets

The following is a link to decision making flow sheets that have been developed to help staff identify the appropriate person to consent to care and treatment for many of the major scenarios that staff experience:

The following are some highlights from each of the above scenarios as well as some additional scenario information:

- A. Children of Married or Separated Parents
 1. Either mother or father may consent when parents are married. It is not necessary to check with or obtain the consent of both parents.
 2. If married parents are separated, either may consent unless there is a court order specifying that one parent is the sole "health care decision maker".
 3. If staff knows that married parents disagree, the parents must reach a mutual agreement regarding treatment or nontreatment.

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B. Children of Divorced Parents

1. The "parenting plan" in dissolution actions designates one or both parents as the "health care decision maker". If both or mutual, either parent may consent. If sole, only that designated parent may consent.
2. In older and out-of-state actions, the term may be "legal custody" (distinguish from "physical" or "residential" custody). If joint legal custody, either parent may consent. If sole, only that designated parent may consent.
3. Either parent may consent to emergency health care.
4. Upon the death of the divorced custodial parent, the noncustodial parent's right of custody revives automatically without any court action.

C. Children of Putative Fathers (Parents Not Married)

1. The natural mother may consent.
2. A putative father may also consent if he has a birth certificate for the child with the father's name on it, a court order or a filed paternity affidavit. The court order may or may not be a "parenting plan" giving him that right.
3. Previously, the father's name on the birth certificate was not accepted as proof of paternity however the Dept. of Health (Vital Statistics) has confirmed that they do not list a father's name on the birth certificate unless proof of paternity, in some form, is established.

D. Adopted Children

1. Any individual that adopts a child becomes that child's parent and is bestowed with all the parental rights to that child.
2. If there is no documentation on the adoption, staff may rely on the parent's representation as noted in the section below entitled "Staff May Rely on Parent's Representation." The documentation is not required, however, if it is provided then it should be filed in the medical record.

E. Children of Non-Parental Custodians

1. A non-parent, most often a grandparent or aunt or uncle, with a court order granting "non-parental custody" of a minor child may consent.
2. Although the parents may no longer have the right to also consent, they may have rights to visit their child.

F. Children in Shelter Care/Foster Homes

1. The court order for placement specifies the agency or individual with authority to consent for health care. This authority typically extends only to routine medical, dental, and psychological examination and care. Additional consent by the natural parent is not required.
2. Elective or non-emergency surgical care including anesthesia requires informed consent from a) a parent whose rights have not been terminated; or b) authorized agency or individual as granted by court order or by other legal authority.

G. Dependent Children with Court-Appointed Guardians

1. For dependency guardianship orders entered as of June 1, 1994, the granting of custody to an individual automatically includes the authority to consent

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- to health care, including surgery and anesthesia. Additional consent by the natural parent is not required.
2. For orders entered before June 1, 1994, the court order must specify that the dependency guardian may consent to surgery. A natural parent whose rights have not been terminated may consent.
- H. Children of Terminated Parental Relationships
1. When a parent's rights are terminated, he or she loses all authority to consent to health care and to visit the child. The termination order grants custody to a custodian who has authority to consent to all health care procedures, including surgery and anesthesia.
 2. One parent may retain the legal right to consent when the other parent's rights are terminated.
- I. Children in Pre-Adoption Process
1. Prior to the entry of an order of "relinquishment for adoption," a relinquishing parent with legal custody of the minor child should consent to health care.
 2. During the first 48 hours of an infant's birth, the health care provider must seek consent from the natural mother or father, if married.
 3. Only upon entry of the "relinquishment order" may the individual or agency appointed as legal guardian and awarded custody of the child authorize health care. A relinquishing parent may have rights to visit the child.
- J. Emancipated and Mature Minors
1. Individuals age 18 years or older may make health care decisions for themselves as well as for their natural born and adopted children.
 2. When minors are married to an individual 18 years or older, these minors are deemed to be of full age and may make health care decisions for themselves.
 3. Minors who reaches 16 years of age may be granted a court determination of emancipation status and make their own health care decisions.
 4. A minor may be deemed a "mature minor" by a treating physician. Factors for consideration include age, intelligence, maturity, training, experience, economic independence, and freedom from parental control. The physician determines capacity to understand the proposed medical treatment and to weigh the factors involved in the informed consent process.
- K. Special Consent Situations for Minors
1. Sexually Transmitted Diseases
Pursuant to Washington State Law (RCW 70.24.110), a minor fourteen (14) years of age or older who may have come in contact with any sexually transmitted disease or suspected sexually transmitted disease, may give consent to the furnishing of hospital, medical, and surgical care related to the diagnosis or treatment of such disease. The consent of the parent or legal representative of such minor shall not be necessary to authorize hospital, medical, and surgical care related to such disease.

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2. Chemical Dependency
Pursuant to Washington State Law (RCW 70.96A.95), a minor thirteen (13) years of age or older may give consent for him or herself to the furnishing of outpatient treatment by a Chemical Dependency (CD) treatment program certified by the department of Social and Health Services. Parental authorization is required for any treatment of a minor under the age of thirteen (13).
 3. Outpatient Mental Health
Pursuant to Washington State Law (RCW 71.34.030), a minor thirteen (13) years of age or older may request and receive outpatient mental health treatment without the consent of the minor's parent. Parental authorization is required for outpatient mental health treatment of a minor under the age of thirteen (13).
 4. Sexuality/Reproductive Rights
Pursuant to Washington state law, a minor fourteen (14) years of age or older may consent to medical treatment concerning his or her sexuality or reproductive rights without parental consent.
- L. Children of Minor Parents
1. The general rule is that parents may consent for their children.
 2. If the parent is a minor and is deemed by the health care provider to be too immature and unable to make responsible health care decisions for his or her child, it may be necessary to contact child protective services. Parents of the minor parent, as the patient's grandparents, do not have the automatic right to consent.
- M. Indian (Native American) Children
The federal Indian Child Welfare Act of 1978 requires that Indian (Native American) children be handled according to federal requirements. Providers should seek legal advice as situations arise.
- N. Developmentally Disabled Individuals
1. The legal representative of a developmentally disabled individual is defined as a parent of a minor child, the legal guardian, the limited guardian, an attorney, or any person authorized by law to act for the other person.
 2. If the minor resides in a residential habitation center (e.g., Lakeland Village, Rainier School, Yakima Valley School, Fircrest School), the secretary of social and health services or designee provides consent.
- O. Incapacitated Individuals with Court-Appointed Guardians
1. When a guardianship has been established for an incapacitated minor (RCW chapter 11), the appointed guardian may consent to most health care.
 2. Examples of exclusions are involuntary commitment for mental health treatment, convulsion-inducing therapy, and psychosurgery.
- P. Juvenile Detention Individuals
1. The administrator of the juvenile court or authorized staff may consent to health care requiring prompt attention for juveniles lawfully detained or sentenced to a detention facility.

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2. Treatment shall not be authorized for juveniles whose parent, legal guardian, or legal custodian informs the administrator of the juvenile court of objections to the treatment before the treatment is provided.

III. Written Transfer of Authority

"The parent or legal representative with health care decision-making authority for a minor patient may in writing permit another competent adult to consent to necessary and appropriate health care for that child in his or her absence. The health care provider should nevertheless make a good faith effort to contact the parent or representative and document the attempt in the medical record if the documentation is not specific to the care being considered. It would be inadvisable for the provider to accept consent from anyone other than the individual with actual authority for certain health care that entails high risk treatment, involved surgery/anesthesia, research therapy, significant management of a new chronic illness, or withholding or withdrawal of life-sustaining treatment." (Washington Health Law Manual).

IV. Kinship Declaration

Washington law allows a hospital to obtain informed consent for care of a child from an adult relative of the child (other than the child's parent) if that adult completes a declaration stating that he or she is a relative of the child and responsible for the child's care. With the exception of emergency situations, we are reticent to accept a declaration for high risk care such as surgery and anesthesia. Staff need to encourage the relative to use the time between clinic appointment and surgery date to get more specific information and documentation regarding their consenting authority from the child's parent/legal guardian or through the legal system. If you have questions about any situation, please contact Risk Management or General Counsel for assistance.

V. Staff May Rely on Parent's Representation

A health care provider may rely upon the representation of a parent that he or she is authorized to consent to health care for the minor patient. Washington State law provides that the health care provider incurs no civil or criminal liability for such reliance.

Submitted by: Risk Management
Reviewed by: Risk Management
Revised by: Risk Management

APPROVED BY:

Pat Hagan
COO

08/11/2006
Date

ORIGINATED:

REVIEWED: 5/02/01

REVISED: 5/13/96; 2/25/99; 2/23/04, 3/31/06, 08/11/06

Exhibit J

Letter from Jeffery Sconyers General Counsel, Seattle Children's Hospital and Regional Medical Center to Deborah A. Dorfman, Director of Legal Advocacy, and David Carlson, Associate Director of Legal Advocacy, Washington Protection and Advocacy System (January 23, 2007)

January 23, 2007

Deborah A. Dorfman
Director of Legal Advocacy
David Carlson
Associate Director of Legal Advocacy
Washington Protection & Advocacy System
315 – 5th Avenue South, Suite 850
Seattle, Washington 09104

Re: Follow-Up to Meeting of January 22

Dear Deborah and David:

Thank you for meeting with Jodi and me on Monday, January 22. We very much appreciated the spirit of collegiality and cooperation of our meeting, and we look forward to working with you in the future.

Jodi is preparing and will send you the redacted version of the opinion letter provided at the time of Ashley's surgery, as we discussed. I am writing to provide you with what we consider to be a preliminary draft policy dealing with Sterilization. I have discussed this policy with our new Medical Director, Dr. David Fisher, and he has authorized me to send it on to you for your review and comment. We very much welcome any suggestions you may have to clarify or strengthen it. Children's is committed to assuring that no sterilization procedure is performed on a person who lacks legal capacity (including, as we discussed, all our minor patients) without a court order authorizing it.

I will be out of town from Wednesday through Friday this week, but Jodi is here to respond to any questions or concerns you may have. Feel free to communicate with either of us as we move forward. Thank you again for your consideration.

Very truly yours,



Jeffrey M. Sconyers
Vice President and General Counsel

Enclosure

C: Thomas N. Hansen, M.D., Chief Executive Officer
Pat Hagan, President and Chief Operating Officer
David Fisher, M.D., Senior Vice President and Medical Director
Jodi Long, Associate General Counsel