

**Welcome to Ashley's blog, dedicated for the wellbeing of Pillow Angels,
prepared by her parents pillowangel@hotmail.com**

This blog received more than 2 million clicks in January 2007, when Ashley's story went viral worldwide.

"Every human life matters. There are no exceptions. There is no hierarchy. The presence of the divine can be seen in the tiniest and most vulnerable just as it can be seen in the strong and powerful." by Timothy Shriver

We appreciate your interest in our daughter's story, which we share for the benefit of other families who might bring similar quality of life improvements to their Pillow Angels.

✿ **Charley's story on TV (New Zealand, May 2014)**

*excellent video
Thought provoking!*

✿ **Our interview, Erica's story & Tom's story (The Guardian, March 15, 2012)**

First Boy R&A

✿ **Our first interview - in writing CNN Health, March 12, 2008)**

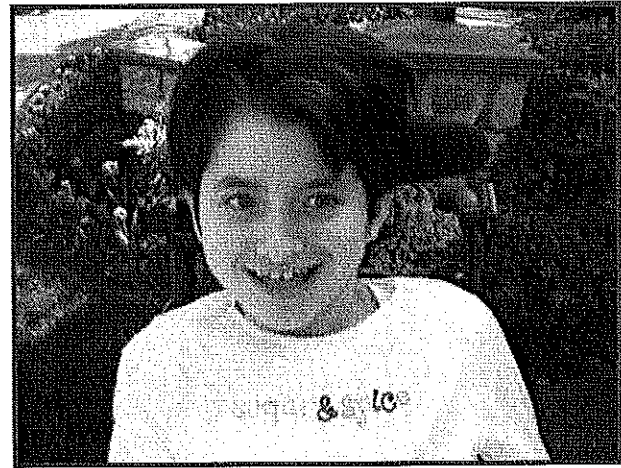
✿ **The "Ashley Treatment", a one slide summary**

Main:

Details about Ashley's condition & the treatment: [article on the "Ashley Treatment"](#) & a [one slide summary](#).

Ashley in December 2011, below in 2000 & 2007





More photos of our beautiful angel: [Ashley along the years](#) and [Ashley in 2007](#); also, [medical photos](#).

Reaction from others: [the testimonies section](#) and [the support section](#).

Also, a [section for general updates](#) and a [section with references and media coverage](#).

Quotes:

Received on May 23rd, 2013

Just learned that our sweet Peter is finished with the growth attenuation treatment! 🤗 His current bone age is at 16 years, his height is 4'6", his weight is 60 pounds, and he is 9 years old. In August 2013 we would have hit our three year mark for starting the treatment. The Dr. said at 16 bone age he could still experience 2% more growth, but she wants us to end the therapy now. She wants to follow up in 6-12 months. WE ARE FINISHED and I am so excited and extremely grateful!!! Everytime I look at my 15 year old son who is towering over me at almost 6'4", I am so thankful we learned about the treatment for children like Peter and went forward when we did. Wish we could have started earlier, but 60 pounds is very 'doable'. Thank you, AD [Ashley's Dad], for all you have done to make this possible! How do we get the word out more so that parents have the choice? So many still do not know about it, it is sad. They find out when it is too late. Anyway, I hope you, your family, and sweet Ashley are all doing well!

a very happy mom of a pillowangel!

Received on March 17th 2012

This is a wonderful interview. So genuine. Your parental love is strong, transparent and inspiring.

Received on March 16th 2012

"The articles still cause me amazement that anyone would criticize this or us. The love and desire to care for our own kids and give them the comforts they enjoy as small people, seems like the least we all could do for them. ... So if loving to see my boy who can't eat or drink, sit, crawl or walk in his swing laughing and giggling and clapping his hands makes me a bad parent then I'm totally cool with that!"

Received on March 15th 2012

"What a wonderful innovative solution to a heartbreaking situation. Ashley is extremely fortunate to have been born in such a loving family. All the best to you!"

Received on May 23rd 2011

"Your story is very moving and touching. The love you have for your daughter is very evident in everything you have done. You have given a public light to an unseen set of issues in our society and done so with courage and the best interests of your daughter.

Unlike many of your other supporters I do not have experience with a 'pillow angel' but understand the blessing I have in my four healthy children. I would like to think I would have been as courageous as you have, but have my doubts. You and your beautiful Ashley are in my prayers and I wish you all the best for a full life with your daughter.

Thank you for sharing your story with all of us, and for doing what was right for this little girl. Thank you also for pointing out the Smile Train and the works they do, I will be making a small donation in the name of your daughter."

Received on July 6th 2009

"I want to thank you for pioneering this treatment to aid all the pillow angels out there in the world today. As a pediatric nurse practitioner I cannot express the sheer horror of watching children grow into adults and have their parents try to move them. I take care of a 17 y.o. male with bilateral femoral and tibia fractures (large bones in both legs) from turning him in bed. He weighs close to 200 lbs. Surgery to repair is not an option as he would never come off the ventilator. I have another patient who is non-verbal with severe fetal alcohol syndrome. When her menses come she screams, will not let you put pads on her and throws the discharge at caregivers. She cannot have Depo because of bone loss risks and we have been unable to stabilize her cycle with the pill. I think if those people who are appalled by the treatment would come and see the children in institutions, developing sores because they are so hard to turn, listen to the parents talk who had to put their children in a institution because they could not care for them at home, and would see the bedridden children/adults who are raped and then die during childbirth, the argument would cease. Thank you for publicizing your treatment. I am hopeful that someday we may offer more pillow angels this same gift and allow them to stay at home with the people that love them."

Other:

Ashley's text and photo material is copyrighted. We hereby grant permission to use Ashley's photos and to quote from this web site and article as long as you clearly credit the site and include the following link: <http://www.pillowangel.org>. Printing copies of the article for personal or educational use is permitted, we suggest a donation to The Smile Train per below. Please email us for any other usage.



If you feel touched by Ashley's story and want to aid vulnerable children we strongly recommend a donation to [The Smile Train](#). It is the fruition of an amazing act of volunteerism that improves the lives of tens of thousands of children worldwide who are born with cleft lips.

Updates on Ashley's Story

January 13th, 2010 (third anniversary)

- ✿ Ashley continues at a stable 65 pounds and 53 inches.
- ✿ Ashley has a serious scoliosis (curvature of the spine) condition. After the end of the estrogen therapy her scoliosis curve continued evolving to 56 degrees as measured in August '08. If her curve reaches 75 degrees she becomes in need for a major back surgery that involves a large incision in order to straighten her spine and protect her organs. Fortunately, Ashley's curve measured at 56 degrees in October '09 (no change in 14 months)!, which gives us hope that she will avert this awful surgery. Does Growth Attenuation slow down the progression of scoliosis? This is an important question to evaluate and better understand, and a potential important benefit to growth attenuation.
- ✿ About a dozen parents all over the world who are successful at providing the treatment to their Pillow Angels (boys and girls) are in contact with us. Some medical institutions are providing the Ashley Treatment while others are not. We know of a case where a hospital's ethics committee approved the treatment, but hospital officials declined to provide it citing PR concerns.
- ✿ Fortunately, the Ashley Treatment, especially the growth attenuation aspect of it, is broadly discussed by the medical community. For example, following are excerpts from a private email I received from an attending doctor of a panel on Growth Attenuation at the pediatric conference held in Hawaii in May 2008:

"The panel session at the Pediatric Academic Societies Meetings went very well. The audience included about 200 pediatricians, many of them endocrinologists. ... Although many of the panelists raised concerns, most seemed supportive of growth attenuation (the focus of the panel) for some children. The audience seemed very receptive. Perhaps most surprising, was that when we asked for a show of hands, about half of the room said they had been approached by a family seeking growth attenuation, and about a dozen raised their hands when asked if they had offered it to a family. Everybody seemed agreed that it should be studied or that a registry should be created if this moves forward. It should be interesting to see what happens in the endocrine community after that discussion."

- ✿ In a symposium about growth attenuation hosted by the Treuman Katz Center for Pediatric Bioethics at the University of WA in January 2009, Dr. Douglas Diekema stated that ethics committees in two major Children's hospitals have investigated growth attenuation thoroughly and concluded that there are no ethical issues with the treatment when provided to a child with similar conditions to Ashley's.
- ✿ In an article titled "Growth-Attenuation Therapy: Principles for Practice" published in Pediatrics magazine, June 2009, two pediatric endocrinologist and two bioethicists concluded as follows:

"Our analysis suggests that growth attenuation is an innovative and sufficiently safe therapy that offers the possibility of

an improved quality of life for nonambulatory children with profound cognitive disability and their families. Pediatricians and other care providers should include discussion of these options as part of anticipatory guidance around the age of 3 years so that, if elected, potential clinically meaningful benefits of growth-attenuation therapy can be realized."

✿ In an article titled: "Ashley Revisited: A Response to the Critics," published in the American Journal of Bioethics, January 2010, two bioethicists concluded as follows:

"Many individuals and groups have been critical of the decisions made by Ashley's parents, physicians, and the hospital ethics committee that supported the decision. While some of the opposition has been grounded in distorted facts and misunderstandings, others have raised important concerns. The purpose of this paper is to provide a brief review of the case and the issues it raised, then address 25 distinct substantive arguments that have been proposed as reasons that Ashley's treatment might be unethical. We conclude that while some important concerns have been raised, the weight of these concerns is not sufficient to consider the interventions used in Ashley's case to be contrary to her best interests, nor are they sufficient to preclude similar use of these interventions in the future for carefully selected patients who might also benefit from them."

December 31st , 2007 (first anniversary)

✿ Ashley is doing very well, she is in stable health (down to reflux medicine only!) and often happy and content under our loving care; see [her photos from 2007](#). She is profoundly dependent on us but also profoundly precious to us, we are privileged to have her in our life.

✿ Ashley today weighs 63 pounds and is 53 inches (4' 5") tall, unchanged from a year ago when we stopped the estrogen therapy! We so wish we could share these success results with Dr. Gunther, who we miss dearly.

✿ We recently finished reading and categorizing a total of 4,705 emails that were sent to pillowangel@hotmail.com mostly in January. Two hundred of the emails were from media agencies worldwide. Out of the 3,903 messages that took a position on the Ashley Treatment 3,665 (93.9%) were in support and 238 (6.1%) were critical of the treatment. These numbers imply that the overwhelming majority of those who took the time to visit Ashley's blog (the only way to obtain our email address) and see her photos were in support. More importantly, virtually all family members and caregivers who indicated a direct experience with Pillow Angels were in support of the treatment. We are evaluating ways to share more of this input, which includes well written and informative gems, while protecting the privacy of those who trusted us with their real life stories. Following are some more stats on the emails we received:

- 1,120 were in support of the treatment and came from family members or caregivers who have direct experience with Pillow Angels.
- 159 messages came from families who indicated that they are pursuing or evaluating the treatment for their Pillow Angels.
- 2,545 support messages came from others (i.e., no indication of direct experience with Pillow Angels).
- 238 messages were critical of the Ashley Treatment, and many of these came from individuals who have disabilities themselves and who reacted to feelings of how inappropriate the treatment would be for them.

- Also of note, is that 115 messages indicated a reversal of opinion about the treatment from negative (based on sensational headlines and misleading media coverage) to strong support after seeing a well cared for Ashley in the photos and reading our article. Many of those apologized for judging us in reaction to headlines and without seeking the facts first.

✎ During the course of the year we had the fortune of meeting many Pillow Angels and their families who are pursuing or evaluation the Ashley Treatment. We're doing what we can to share our experience and help these families help their precious ones. Our advice is that they proceed with focus on the interest of their child; all other considerations should take a back seat to our sacred responsibility as parents to do what we believe is right for our children. We recommend they proceed diligently, carefully and discretely and work with the right specialists to keep their child on a safe path. Since compiling and documenting what is learned from the first wave of therapies will help future generations of Pillow Angels, we encourage these pioneering families to contact us (pillowangel@hotmail.com). We are evaluating the possibility of establishing a safe and private forum to share notes and help one another. Hopefully, this grassroots effort will pave the way towards a formal study on the different aspects of the Ashley Treatment.

✎ In order to continue Dr. Gunther's courageous and pioneering work in helping our daughter attain a better quality of life; we've compiled his notes and ours from Ashley's estrogen therapy together with related lab results and X-rays, to share with families and Doctors, upon request, who are evaluating the treatment for their Pillow Angels. Given that Ashley is the first, as far as we know, to receive this therapy, we want to make sure that Doctor Gunther's careful documentation of her therapy is available to help others.

✎ Performing a Google search for the "Ashley Treatment" and "Pillow Angel" phrases (which were incepted in Ashley's article of January 2nd 2007) resulted with 20,200 and 5,090 page hits, respectively! Ashley's blog is usually the first or second page that results from these searches, which is an indication of the continued high traffic of visitors throughout the year for a total of 2.52 million clicks so far. Even though the term "Pillow Angel" was criticized by a few, it was cheered and embraced by most families and caregivers (i.e., those with direct experience with Pillow Angels) in their correspondence with us.

✎ We've added a [one-slide summary on the Ashley Treatment](#), which enumerates the key points about Ashley's condition, the treatment and its benefits to Ashley, and some concluding remarks.

October 12th , 2007

We are deeply shocked and saddened to learn of the sudden death of Doctor Daniel Gunther on September 30th. His tragic death is a tremendous loss, especially to other vulnerable kids like Ashley and their families, to whom he represented hope.

Our prayers are with Dr. Gunther's family.

Following are related gems emailed to pillowangel@hotmail.com:

God Bless Ashley and her family always. It sounds like Dr. Gunther was amazing. It is a shame that he resorted to this, knowing what he has done for your family and opening the

eyes of the world for others. I can only pray that his work will continue on.

I hope Ashley and her story give the world the benefit that courageous doctor gave you.

Dr. Daniel F. Gunther sounds like an incredible and caring doctor who went to great lengths to do the "right thing".

I wish to extend my condolences for the tragic loss of such a generous doctor who was 'doctor enough' to have dared let his humanity reign supreme. Regardless of how some may 'armchair quarterback' his work (as I think you Americans say - I'm from 'down under') I so respect his fortitude in not taking the 'easy road out' - he could have chosen to send you away when you came to him, as many lesser doctors would have!

I am devastated to learn of Dr. Gunther's suicide. When I heard about Ashley's situation, and what you had decided to do in order to continue to care for her properly, I was so glad that you had been able to find a physician who cared enough for Ashley's future to help her, and you.

I couldn't believe all of the hostility and flak that were directed toward Dr. Gunther, once his article about Ashley's care was published. NO ONE has the right to judge the difficult decisions parents must make in a situation like yours. Dr. Gunther did what he did from compassion, and selflessness.

Ashley is your "pillow angel". Now she has an angel, too : Dr. Gunther. May God bless him always.

I wish to express my total support of you and your doctors in the care of your precious child! I am outraged at the nature of comments and coverage. My heart is broken over the death of this wonderful man, who came as your 'rescuer.' There is more I wish to say, but I will do that later when I have gathered my thoughts.

"I am sure that you were saddened by the death of Dr. Gunther, if I understand fully what this Dr. did for your family and other's like [yours] he will be sadly missed. One can only hope that others will take up his compassion.

...

Often the Hippocratic Oath is miss-quoted, to say that the prime doctors role is to save life, where the true oath is to maintain the quality of life. You and the doctor made the correct decision for your daughter, had I been in a similar situation I only wish that I could hope for your strength."

I am very sorry to hear about the death of Dr. Gunther. I commend him as a researcher, and I hope his family and friends see his work as revolutionary and sincere. He was willing to look outside the norm to improve quality of life for a patient, not simply follow the status quo in treatment for those with severe disabilities. I hope the circumstances of his passing do not overshadow the fact that you and he did what was best for Ashley and not yourselves. We need more researchers and physicians like him.

I am so sorry about the doctor committing suicide. It is really a shame. I know that

sometimes the mind can lie to us and make us feel hopeless and so does God. When he sees God, I know that God will bless him abundantly for having helped Ashley. I hope that in the future, the Ashley Treatment will be available to all pillow angels. You guys are awesome and are changing other peoples lives for the better.

I am writing to express my sympathy over the death of Dr. Gunther. I see from your blog that you held him in high regard and I'm sure his passing will affect you greatly. I feel his work with your daughter was warranted and done from the heart.

"I am so saddened by the news, as I bet you are as well. Dr. Gunther has been my daughter's doctor for several years now, and I can't believe I just talked to him on the phone less than two weeks ago.

I was aware of Ashley and the news surrounding her, and my thoughts were and still are, I would do the same. I am thankful to you for being so brave, to advocate for your daughter the way that you did, and I'm thankful that Dr. Gunther once again did the best he could for one of his patients, even if it meant opening the doors to a big controversy. When I heard your story, Ashley's story, I remember thinking, "Thank you. This will help others (like ourselves and our daughter) to have more options when the time comes. While I'm sure you are so exhausted from the controversy and the devastating news about Dr. Gunther, I just feel the need to reach out and let you know, you're not alone. Those who criticize can't know how it feels to be in your position, because if they did, it seems obvious they would choose the path that you have chosen. For those of us who do know what you're going through or at least have some sense as it "hits us close to home", we thank you and send our heartfelt thoughts your way. We'll never forget Dr. Gunther, and it's incredibly sad that for whatever reason he did this, he must not have known how much he meant to all of us, how much we counted on his opinions and decisions in the care of our children, and how much he will be missed."

May 8th, 2007

Position of Ashley's Parents on the Legal Findings on hysterectomy

As Ashley's loving parents we support the vigilance of WPAS in their effort to protect the vulnerable members of our society.

In 2004 Ashley was indeed given a hysterectomy without a court order. Prior to the surgery, we had consulted with a disability lawyer [see Exhibit-O for the full report] and learned that the state law, which is intended to protect the rights of the disabled to procreate, did not apply to Ashley's case since:

1. Given Ashley's developmental state and prognosis, which is well-documented by her doctors and was reported to the Ethics committee, voluntary procreation is not meaningful or applicable to her case and will never be.
2. Sterilization is not the intent of the Ashley Treatment but a byproduct of it

While we support laws protecting vulnerable people against involuntary sterilization, the law appears to be too broadly based to distinguish between people who are or can become capable of decision making and those who have a grave and unchanging medical condition such as Ashley, who will never become remotely capable of decision making. Requiring a

court order for all hysterectomies performed on all disabled persons regardless of medical condition, complexity, severity, or prognosis puts an onerous burden on already over-burdened families of children with medical conditions as serious as Ashley's.

As responsible and loving parents, deeply concerned for the wellbeing of our child, we provided a better quality of life for our Ashley, who is doing very well under our love and care. We hope that other families of the many children like Ashley will likewise be able to care for and benefit their children without undue obstacles.

We appreciate your continued support, prayers, well wishes, and respect of our privacy.

January 9th, 2007

Upon reviewing some press and TV coverage, we wish the media would be more careful in reading our story and more precise in interpreting and reporting it. We've seen many instances of sensationalist spin and misinterpretation.

For example, the media can explain the motivation for creating this web site as "parents defend ..." or "parents share their learned lessons ..." Most media chose the former, while our motivation is actually the latter.

Examples of misinterpretation that we've seen include:

1. "Parents stop the growth of their daughter ..." our daughter stopped growing mentally and intellectually years ago, when she was a few months old.
2. "Parents removed breasts so that daughter is not sexualized ..." her almond-sized breast buds (not breasts) were removed to prevent her breasts from growing uncomfortably large; we cited the non-sexualization as a side benefit.
3. Some articles fail to clarify up front that our daughter is severely disabled, in a small and extreme category of disability, leaving their audience with the image of a mildly disabled girl -- which is what most people have a direct experience with -- which would indeed make the Ashley Treatment shockingly inappropriate .

January 7th, 2007

Upon much reflection this weekend, we've decided that we will continue to communicate via this web site. We politely decline the invitations for direct engagement with the media. The material we have here tells our story in great detail. We appreciate your respect for our privacy.

We find the worldwide attention to Ashley's story both gratifying and overwhelming. Since we've published this web site the night of January 2nd, the story:

- 📰 Has topped the Health section of Google News for several days – there have been more than 400 articles worldwide
- 📰 Prompted more than 1.6 million hits to this blog so far – more than a million in the first 48 hours!
- 📰 Generated more than 2,500 private emails – more than 1,500 in the first 48 hours

We're trying to find a balance between attending to our lives and our kids, as we should, and following the unfolding of this phenomenon, continuing to communicate our thoughts, and planning any follow-up steps. We truly appreciate the thoughtful comments and

touching support that we're continually receiving. We chose to share this sampling, mostly from individuals who have a direct experience similar to Ashley's story. **This support has been a tremendous source of energy for us and is motivating us to think how we might use this worldwide attention for the wellbeing of other families with Pillow Angels.**

If you have thoughts for us about next steps and if you have support stories we encourage you to share with us via email to pillowangel@hotmail.com. Your input will be used in the future to help other families who might benefit from our experience. We will read every one of your emails and we will treasure some that we will read over and over again. We've been deeply moved by some of you sharing your private stories and photos with us, your Pillow Angels will forever be in our hearts.

Here are our key message points to the press:

1. Ashley is doing well and is healthy, happy, and lovingly cared for.
2. The "Ashley Treatment" is intended to improve our daughter's quality of life.
3. Providing our daughter with this treatment was an easy decision because the lifelong benefits by far outweigh the risk and short-term discomfort associated with the surgery.
4. We wrote the article and published this web site to inform and help other families of Pillow Angels who might benefit from our experience.
5. With the overwhelming thoughtful support that we are receiving we feel even more strongly than before that what we did for Ashley should be more widely known and available to benefit those children who—like Ashley—face extreme lifetime difficulties.
6. Please make sure to read the five emphasized paragraphs in the first two sections of the article, since they convey the essence of Ashley's story.