

The “Ashley Treatment” for the wellbeing of “Pillow Angels”[©]

Ashley’s Condition - severe brain disorder since birth, remains undiagnosed:

- “Permanently Unabled”: infant level mentally & physically, and will not improve
- Average adult size was expected (her body was growing normally)
- Average lifespan is expected (her condition is not terminal)

“Permanently Unabled” children, who we affectionately call “Pillow Angels”:

- Form a new category of disability, survival was made possible through recent medical advancements
- Constitute less than 1% of children with disability, they are the most vulnerable of society
- Are profoundly dependent on their caregivers & profoundly precious to their families
- Their quality of life is much richer under their family’s loving care, versus getting “warehoused in institutions”
- The overwhelming majority of their families & caregivers believe that increased weight & size is their worst enemy
- An extreme condition that calls for individualized options in the hands of parents to help their children

The “Ashley Treatment”

- Preventative medical care

Reasons for providing the treatment

- **Primary benefit to Ashley**

- **Additional benefit to Ashley**

Side benefit

- **Improves Ashley’s quality of life**

- Makes it easier to care for Ashley
(benefit through symbiosis with caregiver)

Ashley went through puberty by age nine

Remarks on the “Ashley Treatment”

- Appropriate for children with similar condition to Ashley’s
- Relatively safe and leads to significant, lifelong & direct benefits to these children, in the avoidance of pain and suffering & the improvement of their quality of life
- No amount of state funding or resources would replace these direct benefits
- We received 1,150 emails from parents & caregivers who have direct experience with Pillow Angels, & who expressed a strong support for the treatment
- Dozens of parents of Pillow Angels worldwide are evaluating the treatment for their children

“Breast Bud Removal”

- Removal of almond size glands that enlarge upon puberty
- Simple surgery if pre-puberty
- **Eliminate discomfort caused from large breasts, laying down or in supportive harness**
- Eliminate possibility of fibrocystic growth
- Eliminate possibility of breast cancer
- Avoid sexualization towards caregiver

Hysterectomy

- Removal of tiny uterus
- Alternatives considered, not nearly as effective
- **Eliminate menstrual pain & cramps**
- Eliminate bleeding
- Eliminate possibility of pregnancy
- Eliminate chance of uterine cancer

Appendectomy

- Commonly done with abdominal surgeries
- Eliminate possibility of Appendicitis (5% chance)

“Sizing for Wellness”

- Estrogen therapy (patches) for two yrs to speedup puberty/closure of growth plates
- 40%, 20% reduction in weight, height
- **Increase mobility thru caregiver** (more activities, circulation, stretching)
- **Increase chance of living at home** (versus institutionalization)
- Decrease chance of needing scoliosis surgery, by slowing its progression
- Decrease chance of bedridden induced infections
- Physical self closer to cognitive self

- A two hour surgery when Ashley was almost seven
- About as risky as a tonsillectomy
- Done before Estrogen therapy, since Estrogen causes: 1) rapid growth of breasts & uterus, thus a future surgery becomes more involved & risky, 2) increased chance of tumor in these organs & 3) hard to control uteral bleeding

Prepared by Ashley’s parents

with input from “Friends of Pillow Angels”

For more details see Ashley’s blog by searching for “ashley treatment” or “pillow angel”

Contact us by emailing pillowangel@hotmail.com