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## **Crusade for Change: Annie's Story and a Mother's Mission**

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*"Every child, every person needs to know that they are a source of joy; every child, every person, needs to be celebrated ..."- Jean Vanier, International Humanitarian*

*"We trusted," says Barbara Farlow, mother of Annie, born with a serious genetic condition associated with disabilities called Trisomy 13.*

### **Annie's Life and Death**

Most infants born with Annie's genetic condition die shortly after birth; few live past the age of 10. Despite these odds, Barbara and her husband Tim decided, after much research and deliberation, that the right thing to do, for them and their family, was to give Annie a chance and to make medical decisions for her in the same way as a child without disabilities. The Farlows were assured that Annie would be treated like any child, and that if surgical considerations arose, they would be discussed and a decision would be arrived at mutually with the physicians.

Annie was born full term and received excellent supportive care at a Toronto hospital for the first several weeks. In August 2005, when she was not yet three months old, she suffered episodic respiratory distress. Annie died within 24 hours of arriving at the hospital. At that time, her parents believed that she would not have survived surgery and that her death was natural.

After obtaining the medical records and discovering the shocking facts of Annie's last hours, Barbara and Tim Farlow made an exhaustive effort to seek answers and a resolution with the hospital. When this effort failed to yield much beyond an insincere apology and token, ineffective plans, they believed they had no choice but to sue the hospital and two doctors involved. The allegations included practicing a policy of non-treatment for children with certain genetic conditions and secretive euthanasia. Annie's story is a multi-faceted case including allegations of violation of civil laws of consent and violation of international human rights laws, including the Convention on the Rights of the Child.

## **Trust at the Center**

Barbara and Tim Farlow liked and trusted their primary care doctor and believed that they shared a partnership with Annie's medical care. However, after Annie's death many doubts and unanswered questions began to surface about the cause of Annie's death, leading to a steady erosion of trust.

Numerous violations of trust occurred: lack of accountability, lack of transparency, lack of respect for human life and the family's decisions, covert withholding of care, and many confusing, conflicting responses or non-responses in meetings with the hospital and the Coroner's Office.

"This world class hospital places patient-centered care very low on their list of priorities, at least when it comes to certain infants with predicted disabilities," says Barbara Farlow. There's no conscience there, no strong leader that will fully admit to the mistakes and make effective improvements beyond token recommendations."

"Annie's medical care was a facade," says Barbara. "The doctors and head pediatrician ignored the multiple, critical indications that revealed that Annie was headed for a respiratory death for most of her short life. Yet the doctors said nothing and led us to believe that Annie was receiving care without limitations. The medical system clearly was never going to save Annie's life or even provide a diagnosis for her. The description of a risky surgery upon which we had provided DNR consent had no diagnostic basis."

The Farlows tried to repair the trust that had been violated by offering to meet with the doctors. The doctors refused. The hospital president offered that they might make a presentation to the Board of trustees, but when the parents pushed for a date in writing, the president reneged.

## **The Issues**

"There are two major issues in this case," explains Barbara. The first is around the issue of consent, consent for infants born with a genetic condition, particularly those that could be detected and terminated before birth. Barbara has discovered hospital plans that specifically dictate a palliative plan of treatment for children based only on their genetic labels, independent of their unique medical condition and the parents' wishes and consent. Barbara believes that there is something very wrong with this.

The second issue deals with the multiple narcotics violations that occurred in the final hours of Annie's life. The family's call for an inquest into Annie's death was denied, despite letters of support from all of the major disability groups in Canada. The coro-

ner is unwilling to provide information to which the family is lawfully entitled. The Minister who oversees the Coroner's Office is also refusing to provide answers. In the final three and a half hours of Annie's death, medication was given without a doctor's order, lethal quantities of narcotics were removed without a doctor's order, and no medication report was issued. "This is scandalous," says Barbara. "We need to be sure that there's consent and transparency and controls regarding narcotics. Right now, based on our experience, that's not the case."

### **Improving the System**

Along the way, the parents had offered to drop the case in exchange for a meeting with top administration officials. Barbara Farlow proposed the idea of an annual lecture and award in the name of Jean Vanier, international humanitarian. Barbara explains, "Our vision was to involve disability groups in a nomination and selection process. Through this process of awarding a doctor who exemplified compassionate, non-discriminatory care for a child with disabilities, we believed that we could affect a positive cultural change."

The hospital responded by agreeing to invite Jean Vanier to speak but limiting an award and lecture, which they refused to have named after Jean Vanier, to only three years. Also, there was a refusal to involve the disability groups in the nomination and selection process. "We rejected this offer," says Barbara, "because we did not believe that the hospital understood the spirit of the proposal. We wanted to meet to discuss and finalize plans together, and shake hands in a gesture of good faith that would result in healing and peace. We were saddened that they did not accept our proposal as offered, as the idea had been very well received by many in the medical and disability communities with whom we had shared it."

Barbara and her husband Tim will carry on, representing themselves and acting as their own lawyers. Barbara comments that, mostly, it's a disadvantage because you don't know half the rules of the game. Yet, they have spent tens of thousands of dollars in legal expenses with no hope of any return and they cannot spend any more. They are continuing to press for answers regarding the issue of the missing narcotics. It is only recently, four years after Annie died, that the Chief Coroner of Ontario finally provided the Farlows with a specific cause of death: central hypoventilation, which is the major side effect of a narcotic overdose. The Chief Coroner has refused to admit or deny that narcotics caused Annie's death.

Summing up her thoughts, Barbara states, "While our journey did not finish in the way we preferred, with a successful, effective collaboration with the hospital, maybe all is not lost. It may be that the legal challenge will yield other benefits by way of affecting change in the system." Barbara's objective in fighting this crusade on behalf of her

daughter Annie is to attempt to “ensure that what happened to us won't happen to other families.”

### **Making a Difference**

As a result of the pain and anguish of suffering the loss of Annie, Barbara has become an ethics and patient-centered care advocate, traveling extensively to talk about Annie's story and the importance of ethics and patient-centered care to hospital associations, medical schools, universities, advocacy groups, the World Health Organization, and other international health and patient safety organizations.

To date, nine newspaper articles and two TV news stories have covered the case. In addition a “Justice for Annie” group was initiated by a professor who heard of the case, and its membership includes many major disability leaders. The High Commissioner's Office for Human Rights in Geneva, Switzerland is also following the case.

Annie's mother explains, “The belief that all lives have value epitomizes the issue of my daughter's case. This means that life should be respected in terms of providing palliative care for suffering, or providing life saving treatment if it's in the patient's best interests. All that we wanted for Annie was a diagnosis and appropriate treatment plan. We accepted her disabilities yet it appears that the system did not.”

“Annie's story is unique within patient safety. The case is not about a medical error in the traditional sense. It's about policy, practice and human rights. We need to develop policies that treat children ethically. We also believe that policies that withhold care from children with certain disabilities should be known to the public. The “values of the majority of the public” is factored into the development of government rationing policies. Barbara finds this concerning ... “What about autonomy and human rights?”

### **Lessons Learned**

Annie's mother stresses that people aren't bad; the systems are bad: “the doctors go with the flow ... it's the medical culture.” When asked to identify any overall messages from this mother's crusade, Barbara states that consumers and the various special interest groups need to become involved and aware at the policy level, especially in a socialized medicine system. She also offers the following advice to the American medical system, as the U.S. debates health care:

- Develop policies with public involvement. Ensure they reflect constitutional rights.
- Doctors: Be ethical. Always be upfront and honest.
- Policies that limit treatment must be overt. In this way, doctors can act honestly, and not risk losing patient and family trust .

- Act compassionately, be transparent and fully admit to wrong doing. Apologizing for poor communication only adds insult to injury.

**For more information on Annie's story:**

- Annie Farlow's Web site: [www.anniefarlow.com](http://www.anniefarlow.com)
- Facebook group – Justice for Annie

***Remember ... It's All About Trust!***