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## Ashley House: A home for medically fragile kids

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Sipping and blowing on a plastic mouthpiece, Gilbert John moved his head back and forth as he tended a virtual aquarium on a computer screen at Ashley House. From a wheelchair in his bedroom, the 9-year-old boy was in total control of the “My Sim Aquarium.”

Using his mouth and head like a computer mouse, he easily fed the computerized fish.

When he was 18 months old, Gilbert fell off a sofa and broke his neck, making him a quadriplegic. He breathes through a hole in his throat using a portable ventilator. He has constant nursing care.

His life at Ashley House is the only one he's ever known.

Last week, two doctors and a medical program administrator from St. Petersburg, Russia, visited the Enumclaw care facility. They're helping design their country's first free-standing facility for medically fragile children and wanted to see what the Ashley House organization and children like Gilbert could show them.

They were impressed at what they found, they said through an interpreter. They liked the homelike atmosphere and marveled at the wealth of health care equipment.

Their guide was Mike Pugsley, who has been with Ashley House even before it opened in 1989 in a 10,000-square-foot estate house in Enumclaw. Over the years, the operation added smaller homes in Tacoma's Browns Point, Olympia and Kent. A fifth home is to open in Northshore in Federal Way.

At present, 25 children live in the four homes under the care of Ashley House, which has a \$4 million annual budget and 70 staff members.

The youngsters come because of traumatic head injuries, birth defects or genetic disorders that require machines and nursing care to help them live. The state pays for most of the care.

## TRANSITION BETWEEN HOSPITAL, HOME

“This is about the kids,” said Bruce Brandler, Ashley House's new executive director and the former head of the now-closed Puget Sound Hospital in Tacoma.

“Not so many years ago, these kids would have ended up in institutions, being warehoused,” he said. “Some saw them as rejects. We certainly don't.”

Ashley House is not meant to offer permanent care, he said. It partners with Mary Bridge Children's Hospital and Health Center in Tacoma and Seattle Children's Hospital to bridge the gap between hospital care and care in a foster home or at home.

“It's kind of a huge safety net for a lot of our families,” said Gail Bermingham, a registered nurse case manager for Mary Bridge.

“Ashley House provides an intermediate step for transition to home,” she said. “It replicates home so much. They have a

bedroom. They come out to a living room. They eat together. They are down on the floor playing with the staff. It's a good place.

"The hospital is not the place to grow up."

The Enumclaw facility has three rooms for visiting parents to stay overnight.

Some children like Gilbert stay longer at Ashley House because they need long-term palliative care or hospice care or because there is no place else for them, Bandler explained.

Ashley House's first patient was a 17-year-old girl who'd been hit in the face by a side mirror on a pickup truck as she tried to cross a highway. She lost an eye, needed a tracheotomy and was in a coma from the brain injury.

The girl eventually woke up and began walking and talking. Photos of her holding some of the babies who lived at Ashley House are on display.

At one time as many as 16 children lived at the house in Enumclaw. Today it's licensed for six; five are there at the moment.

One of them is Cianna, a 3-year-old in a coma because of a birth defect. Therapists come to move her muscles and read to her.

The corner of the Blue Room, where she lies in a crib, is decorated with pictures and colorful drawings. A gauzy white curtain folded to resemble a cloud hangs overhead.

"She seems like she is coming out of it," Bandler said. "I'm a man of faith. Anything is possible."

## **STATE SOCIAL WORKER'S DREAM**

Over lunch with his Russian visitors, Pugsley told the story of Michael Straub, a young state social worker who in 1987 had a dream to create a place to help fragile kids. He got the attention of state leaders, and a task force looked at a variety of issues.

"Our recommendation was the state needed to do something between the hospital and the home but not nursing homes," said Pugsley, who was on the 43-member task force.

That led to the birth of Ashley House.

Its past mirrors the situation in St. Petersburg in many ways, said Peter Anderson of the Sister Churches Program in Seattle. A young Russian Orthodox priest named Father Alexander had a similar dream, recounted Anderson, who accompanied the Russian group to Ashley House. The priest began an at-home care program that today serves 200 children with a staff of 40.

Alexander is leading the effort to create a freestanding facility for eight children, Anderson said.

## **TO HIM, HE'S THE NORMAL ONE**

After watching cartoons for a while in the Blue Room, Gilbert headed back to his room to play computer games. His favorite is "Monster Jam." His favorite monster truck: Grave Digger.

"I like to crash," he said, flashing a smile that lights up his room.

During the week he attends nearby Westwood Elementary School, where he is in a regular third-grade class. Math is his favorite subject.

Photos of fellow students are tacked on a bulletin board. Seattle Mariners posters fill part of one wall. A photo of Gilbert with race car driver and Enumclaw hometown hero Kasey Kahne, who came to see him, has a special place on the wall.

Kevin Sartain of Puyallup is the primary care nurse for the five patients at Ashley House in Enumclaw. He knows them all intimately. Sartain, 40, and Gilbert play video games together. Gilbert beats him all the time.

Gilbert never feels sorry for himself, Sartain said.

"To him, he's the normal one," he said. "We are not."

### **State funding for Ashley House appears stable**

Over the past 20 years, more than 500 youngsters have lived in Ashley House facilities. Despite the state's estimated \$8 billion budget deficit, no cuts are contemplated in funding for Ashley House or the other two similar facilities in the state, said Alan McMullen, who manages the state's \$23 million Medically Intensive Children's Program.

The statewide program supports 212 children with home health care and medical equipment in private homes, foster homes and nonprofit residential facilities such as Ashley House. It also saves the state money, McMullen said.

"The average cost to be in a neonatal intensive care unit (in a hospital) is \$2,700 a day," he said.

"The average cost per day at Ashley House is about \$620."

### **Learn more about Ashley House**

Call 360-825-6525 or 800-853-8120, or visit [www.ashleyhousekids.org](http://www.ashleyhousekids.org)

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