



Bob Gay/The Dominion Post Photos

**Olivia Helmick-Johnson**

# Almost perfect

**BY KIM ORIOLE**

For The Dominion Post

**Olivia** Helmick-Johnson is a happy, apparently healthy little girl who's tall for her age and has a disarmingly joyous smile.

But inside her two-and-a-half-year-old body beats a deformed and crippled heart that doctors in West Virginia can't fix.

That led her mom, Jennifer Johnson, into a 14-month struggle to get **Olivia** the surgery she needs to make her heart normal.

And a struggle it was, but Johnson pressed on, knowing **Olivia's** heart was ticking on borrowed time.

Finally, **Olivia** was approved for the operation she needs to give her a normal heart, and she will fly to Michigan the second week of July for open-heart surgery.

It's a happy but still stressful time for Johnson, 24, as she prepares her daughter for an operation that will detach then reattach both main arteries in

The problem was, there was only one doctor in West Virginia, Pennsylvania or Ohio who had done this particular heart operation, and he'd done it only once. That wasn't good enough for Johnson.

Especially when **Olivia's** cardiologist at WVU, Dr. William Castillo, found a surgeon at the University of Michigan who was experienced at the operation **Olivia** needs. "I appealed their decision because I want the best for my daughter," Johnson said.

Castillo agreed. "They have done probably 50 cases," he said. "I have no knowledge of any other place having that much experience."

**Olivia** was born Dec. 4, 2003, seemingly healthy after a normal pregnancy. But doctors immediately heard a murmur in her heart, and that led them to a grave defect called Levo Transposition of the great arteries, where both of her ventricles and the arteries that feed them are switched



House of Delegates, was immediately taken with Johnson's dilemma, and she vowed to help for free, saying this was the kind of pro bono case lawyers love.

It took months of phone calls and letters and wrangling, but it never came to an adversarial hearing, she

and all the medical bills would be paid.

Now, Johnson faces another battle — coming up with the money to accompany her daughter for the two weeks or so that she'll be in Michigan. As a young mother of two girls — **Olivia** and 15-month-old Elizabeth — Johnson said

her heart.

"I'm just scared of two things now — I'm scared something bad will happen to her in the surgery, and I'm scared we'll go up there and she'll have the tests and won't be a candidate for the surgery," Johnson said.

So Johnson's fight for her daughter's health is far from over.

But she is relieved to have the first step — the approval from Olivia's insurance company — out of the way now.

Olivia is on state Medicaid under The Health Plan, and the insurance company told Johnson she would have to get her daughter's surgery within the plan.

That means the artery and ventricle that are supposed to pump blood to her lungs instead send blood to her body, and the side that is supposed to pump blood to her body sends it to her lungs.

That's a problem because the ventricle for the lungs is too weak to push blood throughout the entire body.

Since Olivia is so tiny, her heart has been able to keep up, and it hasn't been a problem yet.

But Castillo knew it was only a matter of time until it became a serious problem. So serious that he told Johnson her daughter would need a heart transplant unless her arteries were switched to pump

blood in the correct way.

"I just didn't want to sit here and wait for something to go wrong," Johnson said. "I was just afraid if we waited, she'd get too bad and they wouldn't be able to do the operation. I didn't want her to be five or 10 years old and have to have a heart transplant."

When Johnson brought Olivia home from the hospital, nurses told her if Olivia's lips and tongue turned blue, or if she stopped breathing, Johnson was to bring her in.

That was just too nerve-racking for Johnson, always checking to make sure Olivia's color was good,

always wondering if today was the day Olivia's heart would give out.

On the outside, Olivia seemed normal.

She was talkative and loved to play and laugh and flirt with visitors to their apartment, but she got tired more easily than a normal toddler, and that wore on Johnson's mind.

So Johnson and Castillo appealed The Health Plan's original decision to deny Olivia the trip to Michigan, and Johnson knew she needed legal help to fight the insurance system.

Barbara Evans Fleischauer, a Morgantown attorney and fall candidate for

said.

"It was one of the most satisfying legal experiences I've ever had," Fleischauer said. "We didn't have to go to hearing. The Health Plan was reasonable; they understood what we were trying to do. They ended up being very decent in all this."

Bob Kota, general counsel for The Health Plan, said his agency first wanted Olivia to go to the Cleveland Clinic, an in-plan hospital.

But while Johnson was appealing, the surgeon in Cleveland retired, so The Health Plan agreed to the move to Michigan.

Johnson got the word in April that Olivia could go to Michigan for her surgery,

she doesn't want to beg, but would "greatly appreciate" any financial help anyone would like to give her.

She said the girls' father, Bernard Hart, 37, helps her with them, and will keep Elizabeth during Olivia's operation, but money is still tight.

She hopes to use the Ronald McDonald House in Michigan, but said she can't make reservations and will only get in if there's an opening, so she's planning on \$700 to \$1,000 for a motel, plus food for the trip.

Johnson said she was surprised and gratified that Fleischauer wanted to give her legal help for free, and now she's hoping for the kindness of other strangers.