

# YOUTH FEATURE

## Facing disease with determination

By Mike Latona  
Staff writer

ROCHESTER — On many Sundays throughout the year, Jose Rivera and his sister, Jolanda, are quite visible to parishioners at Church of the Annunciation.

Both Jose, 14, and Jolanda, 20, are altar servers at their parish, located at 1754 Norton St. In addition, Jolanda began duties as a Sunday cantor this past year.

Yet there are also weekends when Jose and Jolanda must suddenly cancel their plans to assist at Mass, because they are literally in so much pain that they can't get out of bed.

Both are afflicted with sickle-cell anemia, and the disease's symptoms make it difficult to predict their schedules in either the short or long term.

Sickle-cell anemia is a blood disease resulting from a defective hemoglobin molecule. It affects approximately 72,000 Americans whose ancestry is mostly African, Middle Eastern, Mediterranean or Indian.

Approximately one in 12 black Americans suffer from the disease, which is characterized by sudden, severe attacks of pain. Although medical progress in recent decades has led to more effective painkilling approaches, there is currently no known cure for sickle-cell anemia. Average life expectancy for sickle-cell patients is 42 years for men and 46 for women.

Jose and Jolanda were detected shortly after birth with the anemia. On the other hand, their brother Orlando, 18, and sister Michelle, 30, do not have any sickle-cell symptoms.

Jolanda's illness is concentrated primarily in her ankles. Jose's condition is more severe, extending to several parts of his body.

"It's been a long struggle, and being a single parent makes it even harder," remarked Jose and Jolanda's mother, Willie Mae Neal. She was forced to leave her job at Eastman Kodak Company to care for the children, and now relies on social-service support to make ends meet.

Neal also values the considerable spiritual backing which Annunciation Church's parishioners extend toward the family.

"It really helps a great deal. People are very supportive," she said.

The disease's unpredictability frequently leaves Jolanda's and Jose's lives in a state of flux. Jolanda, for example, had to put her studies at Monroe Community College on hold after an attack



Wendy Longlade/Photo intern

From left: Jose and Orlando Rivera, their nephew, Maurice, sister, Jolanda, and mother, Willie Mae Neal, pause for a photo after a recent Mass at Rochester's Church of the Annunciation.



Jose is an altar server at his parish.

last fall forced the Nazareth Academy graduate to stay off her feet until just recently.

"It's something that you don't really know when it's going to happen. When it does, you have to plan the best you can," Jolanda said.

Jose, meanwhile, went from serving at 9 a.m. Mass on Feb. 12 to a severe attack just one day later that sent him to



Jolanda began serving as cantor this past year.

the hospital.

Despite their medical struggles, both siblings are intent on conducting their lifestyles as normally as possible.

Jose, an eighth-grader at Rochester's Frederick Douglass School, remarked that "this year I made the basketball team, but the doctor said I couldn't play." He is hoping to be well enough to go out for basketball again next year, and he would also like to someday become a singer or actor.

"He's so determined," Neal commented.

As for Jolanda, she hopes to eventually return to college so she can pursue a career in computers or business.

Jolanda emphasized that her determination is heightened when others warn her not to set her goals so high because of her ailment.

"I'm just the type of person who's really ambitious," she said. "People can't tell me when to stop; it's my body and I'll know how far to take things. God is the only one else besides you who knows. Only God knows your future."

## Musical will take place at Nazareth Academy

ROCHESTER — Tickets are on sale for Nazareth Academy's presentation of *The Secret Garden*.

This musical will be presented at 8 p.m. March 3, 4, 10 and 11. A matinee is also set for 2 p.m. March 5. All shows are in the Nazareth auditorium, 1001 Lake Ave.

Tickets are \$7 for adults, and \$6 for senior citizens and children under 12. The building is handicapped-accessible. To reserve tickets, call 716/458-8583.

## Catholic Women's Club accepting contest entries

ROCHESTER — Entries are being accepted for the Marie McCann Award, sponsored by the Catholic Women's Club of Rochester.

This honor is presented — along with a stipend — to a Catholic girl attending either Catholic or public high school who is in her junior or senior year. Candidates should reflect Catholic ideals in their daily life, home, parish, school and community.

Application forms and letters of recommendation are due by March 15. For details, call 716/461-9173.

## Color guard triumphs at Boston competition

IRONDEQUOIT — The color guard and performance dance ensemble from Bishop Kearney High School is enjoying another highly successful year.

Kearney, the two-time defending world champion, won the Winter Guard International New England Regional Crown in Boston on Feb. 5. BK scored 82.1 out of a possible 100 points to win the Scholastic World Class division. The guard also placed second overall in a group which included independent and collegiate teams.

## BK candy sale to begin

IRONDEQUOIT — Bishop Kearney High School is sponsoring its second annual candy sale.

Students will be selling candy from March 1-14. Proceeds will benefit various BK student programs.

Call 716/342-4000 for further information.

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