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## **Diving right in; West freshman lives life to its fullest despite growth-inhibiting diseases**

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"Now for West, Rachel **RoseFigura**. Inward one-half twist."

**RoseFigura** hears the announcement as she walks three steps up to the diving board and slowly makes her way to the end. She turns around and places her tiptoes on the edge.

This is not her favorite dive. She sometimes worries about hitting her head on the board on the way down.

By now, everyone at the East vs. West swim meet is quiet -- partly because of diving etiquette and partly because of something else.

**RoseFigura** stands 4 feet 6 inches tall and weighs 58 pounds.

What many fans watching don't know is that **RoseFigura** is the victim of two growth-crippling diseases, one extremely rare, that have been diagnosed in the past year.

"I'm one in a million -- literally," **RoseFigura** said at a recent practice.

What the fans don't know is that **RoseFigura** hasn't grown in six years. She is a 14-year-old freshman who looks like a third-grader, also a young woman trapped in the body of a 9-year-old child.

Everyone can see that.

What they can't see is the scar tissue under her upper lip where surgeons in April cut a hole through her sinuses to remove a brain tumor lodged behind her eyes. That same tumor prevented her body from producing growth hormones.

And at each temple and the hairline of her forehead are three difficult-to-see but perfectly placed medical tattoos. They would help doctors align her body correctly for radiation therapy should the tumor return.

**RoseFigura** can feel her toes on the board and her heels hanging over the empty space above the 13-foot-deep pool. She can feel her arms held tightly to her sides like a soldier in formation, the fast beat of her heart, the water on her skin.

Those feelings are much better than the daily sting of a needle that injects growth hormones, trying to do artificially what nature did not.

And those feelings sure beat the stares she gets in the West High hallways most days.

Methodically, **RoseFigura** brings her arms straight out to her sides and pauses when they are overhead.

Few of the 1,938 West students or the 53 members of her swim team really understand a life with Celiac disease. Because **RoseFigura** has lost the ability to process nutrients, her growth has been stunted and she must eat gluten-free foods. She is a girl 7 inches shorter and 48 pounds (nearly half her body weight) lighter than average, according to growth charts from the Centers for Disease Control and Prevention.

Despite that, she launches herself off the board. She completes the dive, but her feet slip apart and her body enters the water at an odd angle.

Teammates and spectators applaud.

She swims to the edge of the pool and checks her scores.

3.5, 3.5 and 2.5. No jubilation, no disappointment, no expression at all. She's only been doing this about two months, and her expectations aren't high. **RoseFigura** is still growing -- as a person and as a diver.

Even if her body isn't quite yet.

#### DISEASE HISTORY

Nobody noticed anything until junior high.

"I've always been small," **RoseFigura** said. "In elementary school, it wasn't so bad. (I was) never that much shorter than anybody else."

Then the girl who'd always struggled to stay healthy started getting sick more often.

"My digestive system was attacking itself," **RoseFigura** said.

Fourteen months ago, she was diagnosed with Celiac disease, which keeps her body abnormally small. According to the Celiac Disease Foundation, it afflicts one out of 133 Americans.

Her entire diet had to change. These days, gluten-free bread and cookies are part of a menu that excludes grain products.

"I miss spaghetti," she said. "I eat Thai noodles, but they're not the same."

What did stay the same was **RoseFigura's** size, which perplexed doctors and her family, who expected her to start growing again.

Then, this April, **RoseFigura** found herself battling a new enemy.

She was exhausted constantly, going to bed early every night, struggling to wake up and sleeping more than 12 hours a day. Her headaches seldom went away.

An MRI revealed craniopharyngioma, a brain tumor diagnosed in less than 200 children a year in the United States. It was lodged near the optic nerve behind her eyes.

Craniopharyngioma doesn't grow or infect other organs. But the tumor put pressure on her pituitary gland, which stopped producing thyroid and growth hormones. Something had to be done fast.

Suddenly, **RoseFigura** was facing major surgery -- and big changes.

"She was in a state of denial," her brother Leon, 20, said. "She wouldn't mention it."

Now, she can look at it with a sense of humor and repeat her favorite saying about the two diseases: "I won the lottery. Twice."

In the middle of the school year, **RoseFigura** flew to Seattle for a four-hour surgery that sliced through her mouth and under her nose to remove the tumor. She stayed at the hospital a week before returning home.

"She was a vegetable, not a happy camper," Leon said. "Now, she's the toughest of all of us, even though she's the smallest."

There's a small chance the tumor could return, doctors have told **RoseFigura**. But a recent MRI showed no evidence of it.

Few people know what she's been through.

"I don't keep it under wraps. It's not that big of a secret," **RoseFigura** said. "But I don't want it to define me.

"I don't want them to say, 'Oh, there's the girl with the brain tumor.' I want them to say, 'There's Rachel **RoseFigura**.'"

#### TAKING UP DIVING

On the one-year anniversary of her Celiac diagnosis, and four months after surgery, **RoseFigura** began diving, one of the few sports her size would allow.

She expected a crash course in everything from tucks to pikes and somersaults.

She didn't realize her size would put her at such a disadvantage.

Fifty-eight pounds can barely move a diving board. There's simply not enough weight to catapult the diver.

For **RoseFigura**, the board operates more like a solid platform, forcing her to jump and try to do what heavier divers accomplish using the board's bounce.

"Once she gets her leg muscles stronger, she can move the board," said diving coach Boris Larson.

To compensate, **RoseFigura** adjusts the board's fulcrum to add more spring, something most divers fine tune for each dive.

**RoseFigura** isn't most divers. She rolls the fulcrum all the way back for her forward dives.

"It's still real stiff," **RoseFigura** said.

Despite the drawbacks, **RoseFigura** already knows six dives, even if she doesn't nail them every time.

"She can do dives I can't do that I've been trying for a long time," said junior Savanah Heiner.

Heiner is West's only other diver and **RoseFigura's** best friend on the team.

"She's someone I can talk to, relate to," Heiner said.

**RoseFigura's** size does bring some advantages. One is that she has less body mass to turn in the air.

"Gymnasts are tiny, too," said head swim coach Melinda Greig, who has been coaching in Anchorage for more than 30 years. "Diving is just gymnastics on a board."

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And because **RoseFigura** is so slight, she doesn't really sink or splash -- even when she misses a dive. Judges may reward that.

But her size doesn't help in the swimming lanes, where **RoseFigura** sometimes fills in.

Most swim racers torpedo under water for several meters after leaping from the blocks. But **RoseFigura** pops out of the water and is into her strokes well before other swimmers break the surface.

They emerge meters ahead, and **RoseFigura** has already lost. The gap widens as the race proceeds, and she finishes last most times.

Her backstroke is identical to her competitors in rhythm and form, but in swimming, body surface is everything.

"It means she can't be competitive in her age group," Greig said. "She'll always be out-turned, out-stroked because she's just out-sized."

That would make many people shy about joining a swim team, but it's something of a family tradition. All six members of **RoseFigura's** family either swam in high school or swim today. **RoseFigura** got involved even before she was even allowed to.

As an eighth-grader at Romig Middle School, she would finish her day and walk across the street to the West High pool, where she served as volunteer team manager for a school she didn't attend.

"She is so organized, she could run anything," Greig said. "When I see her, I am aware of her stature, but she is so capable in everything that you forget about her size."

**RoseFigura** made fliers, took roll and did the dirty work that got the attention of her future teammates.

"She's available. She'll do anything," Greig said.

"She's one of those kids you'd love to duplicate. Can we clone her?"

The swim team is one place **RoseFigura** feels accepted, safe from the stares that are part of everyday life. In the West High hallways, she'll sometimes hear students call her "midget," "leprechaun" or worse.

"You get used to it. You just ignore it. Walk away," **RoseFigura** said. "I don't let people get to me."

It helps that her brother Max is one of the better swimmers on West's team. But the siblings are different.

Rachel is more likely to be in the corner with her head in a book -- "a really thick book," said team captain Luke Miller.

Max likes to be the center of attention. He wore butt-cheek swim shorts to last year's state championships.

When the siblings do interact, though, the roles are reversed.

"When you see them, it's funny because she just dominates him," said Miller. "It's her mere presence."

Just like at home.

"The joke is Rachel runs the family," Greig said. "She could be a CEO. Easy."

TYPECAST IN THEATER

"Let's kill Rachel first."

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Those are the last words out of director David Block's mouth as the rehearsal meeting breaks up at West High's production of "Frankenstein," which opens tonight.

Outside of diving, theater is where **RoseFigura** thrives, an environment with some similarities to her sport.

She is playing William Frankenstein, a 10-year-old boy, whose brother Victor creates the monster. William doesn't make it through the play alive.

"It's a pretty small part, but it's fun because you get to die on stage," **RoseFigura** said. "It's the only time dying is fun."

But how should it be done?

"I think he should chokehold her," Block says to Brian Holmes, the 6-foot-4, 350-pound Frankenstein who dwarfs **RoseFigura**.

Next thing you know, **RoseFigura** is hanging four feet above the stage, gripped around the shoulders by Holmes.

"Nah, it's too easy for him to lift her," Block says.

They'll find another way.

Dying on stage isn't new to **RoseFigura**. "Recently, they've decided to kill me a lot," she said. "I've been eaten, buried alive. Who knows? Next I'll be burned at the stake or stoned to death."

While **RoseFigura** is used to dying, she sometimes tires of being typecast. Size is the one thing makeup, costumes and lights can't change.

In eight years as an actor with both the Theater for Young People and the Alaska Theater of Youth, she has been in a quasi-lead role just once. Otherwise, she's been a fairy, princess, schoolgirl or just a little kid.

"A lot of the roles are for a romantic heroine. I can't get those roles," she said. "I would like to play a lead part, but there's very little chance."

A bane for **RoseFigura** is a boon for directors.

"We needed a young boy," Block said. "I thought I would have to go to the elementary schools. When she came in to audition, my problem was solved."

Almost.

Rehearsal is at the same time as swim practice.

"We made a deal," Block says as Rachel wags her finger at him. "She plays a boy. I let her come in just a couple days a week."

**RoseFigura** soon discovered that her theater experience could help her diving.

"I am used to being in the limelight," she said. "Being in front of an audience, it's the same, everyone's quiet and watching." In her role as William, her job is pretty much to die. As inglorious as it seems, roles like that have helped shape her identity.

Her off-stage one, that is.

"I've learned that on stage you have to be big," she said. "And it's filtered into the rest of my life."

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#### A 14-YEAR PLAN

**RoseFigura** would like to be an art professor someday. Her plan is to get a bachelor's degree in math or science with a minor in art before getting her master's and settling down to teach.

But other goals come first.

"I just want to be 5-2," she says with both fists clenched as if willing herself to grow.

It's a possibility. **RoseFigura** started taking growth hormones a few weeks ago, something she will do every day for the rest of her life. She's on thyroid hormones, too. She has a go-anywhere kit with a precisely measured dose she takes every night, injected into her thigh.

And she's watching closely for results.

"The scale at the doctor's office said I was 59 pounds," she announces to her family in the kitchen of their home near West High.

"Honey, didn't it say 58?" asks her father, Mark.

"Well, 58 and three-quarters," she says.

"Almost 60," her brother Max says.

"Oh, just round it up to 65," said other brother Leon.

He may not want that. Leon is the one stuck with giving his little sister piggyback rides, long after most 14-year-olds would be too big. The countdown to **RoseFigura's** final ride has begun.

With the prescriptions and her new diet, doctors expect **RoseFigura** to reach a normal size.

Some people on growth hormones grow as much six inches in their first year, **RoseFigura** said. Others don't see changes for a while. It depends.

"I'll never be a giant," **RoseFigura** said.

But she may be big enough one day to be the romantic heroine. Or maybe just move the diving board.

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friday in sports

PREP PAGE: High school sports statistics and the Prep Stars of the Week, which normally appear on Thursday's Alaska Preps page, will run Friday with a preview of the weekend's football playoff games.

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**GRAPHIC:** Photos by MARC LESTER / Anchorage Daily News; Rachel **RoseFigura** warms up after competing for the West High diving team at a recent meet. A rare brain tumor halted **RoseFigura's** growth, and at 14 years old, the high school freshman is 4 feet 6 inches tall and weighs 58 pounds.; ; Though her size is a disadvantage in a sport that

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requires weight to bend the board, **RoseFigura** has learned six dives since taking it up only months ago.; ; West High's Rachel **RoseFigura**, right, waits her turn to dive during a recent meet. Medical conditions, including a rare brain tumor, have halted her growth. The 14-year-old says she's gotten used to the comments and stares. "I don't let people get to me," she said.; ; During a rehearsal for the West High stage production of "Frankenstein," Rachel **RoseFigura** is lifted into the air by the title character played by Brian Holmes. **RoseFigura** commonly plays a child in plays, as she does in this one. "I would like to play a lead part, but there's very little chance," she said.; ; **RoseFigura**, center, and the rest of the West High swim and dive team holler a cheer at the start of a recent competition.; ; **RoseFigura** injects growth hormone into her leg at home after diving practice. Craniopharyngioma, a rare benign brain tumor, disabled her pituitary gland. The tumor was removed earlier this year. She'll need to take the hormone by injection indefinitely.; ; Rachel **RoseFigura** talks with her West High diving coach Boris Larson at a meet earlier this season. Because of her size, **RoseFigura** has trouble flexing the diving board. Though her scores are usually low, she continues to compete. She's one of two West High divers.

**TYPE:** Staff

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