

## **We are not what we seem**

**by Olga Craig**

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*Ilizane and Xenia are neither boys nor girls - they are hermaphrodites. Olga Craig learns about the lives of children born into a "half-and-half" life.*

Ilizane Broks raises an eyebrow and drums her fingers on the table. "An actress," she says decisively, nodding her head and widening her deep-set, dark eyes.

"Definitely an actress. That's what I would like to be ... and if that doesn't work out, maybe a career in genetics. Seems appropriate.

"But drama is my first choice. I really like the idea of standing up in front of people and saying: 'Hey, this is me!'" Ilizane pauses, then says wryly: "Or rather, this isn't me. All is not as it seems. I am not as I seem."

Her style of introduction hasn't always been so subtle. When Ilizane was five, on her first day at school, she was rather more forthcoming about who, or rather what, she is.

That day, each child was asked to stand on a chair, tell everyone their name and say something about themselves. Ilizane, in her school gym frock and new, shiny shoes, solemnly clambered up, gazed around and said: "Hello, my name is Ilizane. I'm not a girl and I'm not a boy ... I'm an intersex!"

As Peter, her father, recounts the story, Ilizane, who was 17 recently, punches the air. "Good for me," she laughs. "I can't honestly remember a lot about it, just the teacher saying, 'Don't be silly, you're a little girl'. And me insisting that no, I was an intersex." Father and daughter double up in laughter as they imagine the teacher's shock, confusion and curiosity.

"I encounter curiosity rather than distaste or anything like that," Ilizane says, "although it's obviously not something that I just lob into a conversation. It's something I tell someone once I've got to know and like them. And trust them."

As Ilizane settles into an armchair Xenia, her six-year-old half-sister, hurtles into the room, blonde hair flying. She flings herself onto her sister's lap and the girls tumble backwards together onto the sofa, a tangle of limbs and laughter. "What are you, a what, a herm what?" Xenia demands, giggling. Ilizane wraps her arms around her and tells her: "I'm the same as you, I'm an intersex, I've got XY chromosomes, which denote a boy . . . not XX, which denote a girl . . . but I look like a girl."

Xenia has lost interest. "XYZ . . . ABCDE . . . XYZ," she croons as she clammers onto another chair and begins counting her African beads. "I want to be a princess when I grow up," she confides.

Though half-sisters (they have the same mother), Ilizane and Xenia resemble each other neither in looks nor temperament.

Dark-haired Ilizane is angular of frame, tall and straight-backed, square-jawed and broadshouldered. Karate is her favourite sport. She has little time for make-up or fashion. Xenia, fair and blue-eyed, is, Ilizane concedes, much more "girlie". She loves Barbie dolls and wants beads, bangles and fairytales.

What they do share, however, is a condition called CAIS (Complete Androgen Insensitivity Syndrome). It means they are hermaphrodites, possessing both male and female genitalia. Although they have vaginas, they have testes where their ovaries should be, and no uterus. Neither has a penis. Outwardly they look like girls: in truth they are half and half.

"I think of myself as more female than male, but in reality I am half-male, half-female," says Ilizane. "When I think of myself, how I am, I feel female, and I feel female characteristics are those I display most. But there are times when I see the male side of myself, during karate, for example.

"I definitely felt better when Xenia was born. I thought: 'Wow, another one like me'."

There are, in fact, quite a few like Ilizane and Xenia. In Britain about 1000 babies with this rare metabolic disorder, which doctors refer to as ambiguous genitalia, are born each year. In Britain today there are about 30,000 people living with the condition.

Babies with the most common form, CAH (Congenital Adrenal Hyperplasia), are, unlike the sisters, born with XX chromosomes. They should be girls. They have a womb and ovaries but no vagina. Instead they are born with what resembles a small penis. It is, in fact, a vastly enlarged clitoris.

The condition of Ilizane and her sister is less severe. It has helped, too, that they have been brought up in a free-thinking household. Both Peter and Neil, who is Xenia's father, consider their girls perfectly normal. They have brought up their daughters to accept their condition, to ignore the prejudice of the ignorant and to be proud of their difference.

They have been imbued with a healthy sense of their own identity and worth, and yet are, perhaps, somewhat unprepared for the realities of the wider world where such tolerance is hardly universal. Ilizane, one suspects, has inherited Peter's cool-headed approach.

Neil, Xenia's father, is much more brittle. He pounces upon every nuance he perceives as "judgemental" or "pejorative". He is forever on the look-out for any suggestion that the girls are being portrayed as "different".

"Is it a condition?" he asks wryly, eyebrows raised. "Is the word hermaphrodite insulting? Yes, I would say it is," he says, jaw jutting, as he looks across the kitchen table at Peter.

Peter shrugs and asks his daughter. "No, I don't think either is insulting," says Ilizane. "It is a condition. And I am a hermaphrodite."

Friends, she insists, have been curious but not judgemental. "And no, it hasn't been a problem where boyfriends are concerned," she says stiffly. "Once you get to know and like someone, you tell them. If, later in a relationship, a man rejected me because of it, then he wouldn't be the sort of man I would want to be in a relationship with."

As both girls acknowledge, there is little outward sign of their condition: there is nothing physical that prevents them standing alongside their classmates in the shower. It has made their fathers' decision that they should put off surgery to remove their testes until adulthood all the more understandable.

But, as Ilizane admits, if she had CAH, the more common condition, she might well have opted for surgery by now. And it is here, in the arena of medical opinion, that the girls will find that their upbringing may now match modern thought.

Until about a decade ago children born with ambiguous genitalia were deemed a social taboo: such babies were whisked away at birth by grim-faced doctors, leaving bewildered and confused parents in their wake. Then, the perceived medical wisdom was that such children should be operated upon immediately to remove the "offending" appendages. Rarely was the child told until adulthood.

When Lena Harmon's baby, Patrick, was born in 1990, he was bundled out of the delivery room before his mother could hold him. The next time she saw her infant he was in intensive care, hidden behind a curtain. Although born with a well defined penis, its opening was at the base, not the tip. There was just one testicle and, although it was producing lots of testosterone, in most of his cells there was no Y chromosome, the one that contains the genetic instructions for the body to develop as a male.

"The doctors insisted he was a girl and that they would remove the 'offending appendage' immediately," Lena says. "But I had seen Patrick have a tiny erection. I told them: 'You are not

cutting off anything that's working'." A 20-day battle of wills ensued, with doctors insisting the baby would be better off as a girl, and Lena intent on bringing him up as a boy.

Ultimately, the doctors gave in. "We will," they solemnly announced, "allow you to raise him as a boy."

Two months later doctors again urged surgery, this time telling Lena that the baby's testicle (which contained some ovarian tissue) was likely to be malignant. She agreed to a biopsy and when the surgeon said it showed that the gonad was diseased, she agreed to have it cut off.

"Yet I still had this sense of guilt, that I had allowed myself to be railroaded," she recalls. She pestered doctors for a pathology report.

"When I got it I was devastated," she says. "The first thing I read was 'normal, healthy testicle'. My heart stopped. Now my son is a non-functioning eunuch. Before, he was a functioning male. The doctor just didn't care."

For doctors, the notion that surgery is best dates back to a case in America in 1966. Their thinking was based on the plight of a baby who was born normal and given reconstructive surgery after an accident, but their strategy was applied to all children born with ambiguous genitalia.

The baby, John, was taken into hospital with his twin, Kevin, for routine circumcision. During the operation John's penis was burned, by accident. The baby's shocked parents were told that John could never consummate a marriage or have a normal heterosexual relationship.

At the same time Dr John Money, a respected sex clinician, was expounding his theory that it is nurture, not nature, that defines sexuality. He convinced baby John's parents that castration and a life as a girl was best for their son. In 1967 what remained of the baby's penis was removed, his urethra was lowered and a cosmetic vaginal cleft moulded. His name was changed to Joan.

Over the years "Joan" fought against his feminisation. He refused to urinate sitting down or join the girls' classes, but Money's "experiment" had been hailed a success: the fact that "Joan" behaved like a boy was hushed up. Coupled with the fact that, with surgery, it is easier to construct the genitalia of a female than that of a male, this became the accepted solution.

It was only six years ago, when researchers tracked down the, by now, reclusive "Joan", that the long-term effects were realised. His life had been one of torment. He had endured clinical depression and attempted suicide several times. Finally, five years ago, he underwent a sex change. "I will end life as I began it," he said at the time. "As a male."

When Ilizane was born, Peter and Nancy, her mother, knew nothing of the condition. At the moment of her birth there were the usual cries of "It's a girl!" Nothing seemed amiss. A few

months later the couple noticed a growth in her groin but were told it was a hernia. When it became enlarged Ilizane was admitted for surgery to have it removed. It was only then that doctors discovered that the lump was, in fact, testes. A biopsy revealed she had XY chromosomes.

Doctors were in no doubt, says Peter. "Whip them out, they told us. But we didn't want anything invasive. We can cope as her parents, we told them, and she will be able to cope."

When Nancy was pregnant with Xenia (with Neil, her new partner) she refused tests to determine if her second daughter might also have CAIS. When Xenia was born tests revealed that she, too, had CAIS.

The most crucial long-term concern for both girls is that they will never be able to bear children. At 17, Ilizane doesn't see it as a problem.

"If I want children I can always adopt; there are lots of unwanted children in the world." As she grows older, however, her feelings may be more intense.

"What is interesting," says Neil, "is that theoretically it may one day be possible for Ilizane to father a child", another reason, he says, why she should think long and hard about surgery to remove her testes.

"As an extended family, we see the girls' condition not as a medical problem, but a social one," says Peter. "We have tried to ensure that the girls see themselves as people first."

It isn't always easy, says Ilizane wryly. "A few weeks ago I was filling in a form and I had to tick 'f' or 'm' for female or male. I wrote: 'I find this question insulting'."

Neil claps his hands. "Quite right, too. When are people going to realise we don't just have two sexes? There are males, there are females and there are . . . these super-beings!"

Ilizane and Xenia smile impishly. "Superbeings, yeah. I like that," Ilizane says. "Me too," crows Xenia. "But I still want to be a princess."