



that. I can see the more aggressive side.

"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. Around 1,000 babies with this rare metabolic disorder, which doctors refer to as ambiguous genitalia, are born

**'It's not something that I just lob into a conversation. It's something I tell someone once I've got to trust them'**

each year. In Britain today there are about 30,000 people living with the condition. It is passed along the maternal line (there was a one-in-four possibility of Xenia being born an intersex) and has varying degrees of severity.

Babies with the most common form CAH, Congenital Adrenal Hyperplasia, are, unlike the sisters, born with XX chromosomes.

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 broad-shouldered. Karate is her favourite sport. She has little time for make-up or fashion. Xenia, fair and blue-eyed, is, Ilizane concedes, much more "girly". 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, all squeezed together," 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 can become very single-minded about

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." It is, she admits, something of a conversation stopper. "Well, you can't just say: 'Hello, I'm an intersex, a hermaphrodite,'" she says, still stifling a smile.

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 clambers onto another chair and begins counting her African beads. "I

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 gymfrock 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 is 17 tomorrow, 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,



## WE ARE NOT WHAT WE SEEM

These two children, who share the same mother, are neither boys nor girls – they are hermaphrodites. Here they tell **Olga Craig** about their extraordinary 'half-and-half' life

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: there were no dramatic announcements, no sudden revelations. 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 callous 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, where prejudice and distaste for those who are different is commonplace. 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 "judgmental" 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 judgmental. "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. You trust the fact that, as a friend, they will accept you. 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."

It is a mature and reasoned argument: but it is, albeit understandably so because of Ilizane's age, perhaps naive.

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. In many cases not even the parents were told the full truth. The medical profession, convinced that surgery was best physically and psychologically, often browbeat parents into consenting, with devastating effects.

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 the majority of his cells there

Continued overleaf

# 'Whip them out, they

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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. I think the doctor just didn't care. His reasoning was that this was a hermaphrodite, so everything should be removed."

Similarly when Melissa Cull was born, 34 years ago,

with CAH (she had a womb and ovaries but no vagina and a penis-like enlarged clitoris) doctors insisted surgery was imperative. Doctors could not discern her sex but tests showed that her chromosomes were XX.

Although a formal diagnosis was made, Melissa's parents were never told. All they knew was that she needed surgery. At four she was subjected to a clitorectomy which has removed 95 per cent of sensation. At 12 she underwent a vaginoplasty to ensure she could menstruate and have a normal sex life. It wasn't until Melissa was 18 that she discovered the true nature of her condition.

"I thought I had something like cancer, it was just never discussed," she says. "Nothing prepared me for what I was told."

The effect was disastrous. It has taken much of Melissa's adult life for her to come to terms with her condition. "It is difficult, in relationships, to know when to tell someone, and some men just can't accept it," she says. "After one four-year relationship my boyfriend turned around and said that although he knew it wasn't my fault, he couldn't cope with it. I had thought I could trust him but he threw it back in my face. I was utterly heartbroken. It's made it so hard to begin relationships. Where do you start? And, of course, with the lack of sensitivity, it is all the more difficult. But it shouldn't be a dark secret. It is just one of life's anomalies."

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

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.

Within a few months of "Joan's" first birthday his mother dressed him in his first frock. "He ripped at it, tore it off," she recalls. Over

PHOTOGRAPH: FELICIA WEBB



Ilizane with her father, Peter; and Xenia with her father, Neil

John's penis was burned, by accident, with an electro-cautery needle. A catheter had to be inserted and, since phallic reconstruction was in its infancy, 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.

the years, that first reaction never changed. "Joan" fought against his feminisation. He refused to urinate sitting down or join the girls' classes.

In the meantime Dr 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.

# told us

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. The test was offered, she says, on the assumption that she would abort the baby. She told doctors it was out of the question. She would wait and see. 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 16, 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, and her biological clock begins to beat, 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. "It is other people who make it a problem. 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. "Super-beings, yeah. I like that," Ilizane says. "Me too," crows Xenia. "But I still want to be a princess."

■ *Secret Intersex* will be broadcast on April 5 on Channel 4