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They look female, feel like women and have relationships with men – but their chromosones are male. Let down by the medical profession, their lives have been shrouded in shame and secrecy. That's all about to change. Nicola Gill reports

PORTRAITS Mark Harrison

From left: Dawn Vago and Suz Temko

Suz Temko, a glorious arrangement of blonde hair, long legs and feline blue eyes, was a typical teenage girl the night she got drunk on vodka at a party and subsequently discovered she was intersex.

"I was trying to impress my friend's boyfriend by drinking a bottle of vodka. Not cool. My dad had to pick me up and he was, you know, not angry but most definitely disappointed." But when Temko's hangover seemed to drag on long after her vodka shame had faded, it was her mum she turned to. "I still felt blueuggh days later, and I also found a weird lump in my abdomen. I was 15; I hadn't had a period. I asked my mum if feeling rubbish and having lumps was some peculiar puberty thing no one had mentioned."

It wasn't, and several tests later it turned out the lump was actually several lumps of very aggressive cancer. Surgeons operated quickly, but while she was still waking up from the anaesthetic her anxious parents had another bombshell to deal with.

What had been presumed to be cancerous ovaries were actually gonads that hadn't developed into fully formed testes, and instead of possessing a matching pair of female XX chromosomes Temko's were male XY ones. "My parents were told all this along with the news I'd need several months of hardcore chemo. Understandably, when I came round, they decided to not tell meI had gonads and XY chromosomes, figuring we'd deal with that, somehow, later." Later came when she was 16, after an all-clear from what Temko still thought was ovarian cancer – pretty much unheard of in a 15-year-old – when her parents took her to see consultant gynaecologist Professor Sarah Creighton at University College Hospital in London.

"She sat me down and basically said, 'You know how you've been wondering how a 15-year-old girl could get ovarian cancer?' And I said, 'Yes! How the hell did that happen?' She drew me a diagram and explained, 'Boys are usually like this; girl are usually like that. But you are different.' She went on to say that what the surgeons had removed were not ovaries but internal gonads, which had not developed into testes. And the reason I had them was that my body was supposed to develop typically male but for various reasons hadn't. My initial reaction was, 'That's a fascinating biology lesson. Thank you very much.' I left the room with my parents and that's when it hit me. I took two steps and crumpled."

Temko, now 24, a political strategist and also campaign manager for support group Intersex UK, has Frasier syndrome. She feels female, dates men, certainly looks every inch a woman – but has male chromosones. It is one of a wide range of conditions that used to be called hermaphroditism, but are now called intersex variations (or sometimes differences of sexual development). This isn't about feeling you are one gender when you were born another, or your sexual preferences; it's basic biology. Some people with intersex variations say they feel truly "in between" the sexes; others identify strongly as male or female no matter what their chromosomes and genitalia might suggest. "We make up not a third sex, as some people have called us, but something more like a constellation of sexes," says Temko.


Holly Greenberry

'SURGERY IS INTERSEX GENITAL MUTILATION. SCALPELS DON'T SCULPT GENDER'

But the most surprising thing about intersex people isn't that they are a cocktail of what we traditionally see as "male" or "female", but that there are so many of them. According to figures, 1 in 2,000 people are born with genitalia considered atypical enough to prompt medical investigation.

It's hard to grasp at first. For a start, where are all these people supposedly in plain sight who are defying our neat notions of gender? This is where a tale of seemingly simple if curious biology turns more sinister. Holly Greenberry, 38, is co-founder Intersex UK. "I was born with a healthy intersex body and diagnosed with partial androgen insensitivity syndrome (PAIS), meaning my body was partly unresponsive to male hormones, and my anatomy was atypical. My family were offered no support and I was raised as a little boy until it became painfully apparent growing up that I was a girl. But my internal and biological differences were never properly explained to me or my family. I was incredibly fortunate to be raised in a loving, supportive environment, but if I'd had any sort of professional emotional support, it would have made life significantly easier."

She doesn't want to go into details, but the stream of operations through her childhood, twenties and into her thirties, some trying to reverse earlier surgeries, some to repair procedures that deteriorated as she grew up, have left her physically scarred, led to enormous complications and a cycle of further hospital admissions.

"I felt I was unique and alone," says Greenberry. "I turned down many opportunities early in life and struggled educationally. I walked away from a great modelling contract in my late teens because I couldn't handle anything about my scarred body, and my emotional life was a train wreck. Taking artificial female hormones to replace the natural hormones which my body can't make has also left me experiencing difficult HRT-related symptoms." She has since pursued successful careers in both television and property, but current legislation and her wrongly assigned sex at birth means she cannot legally marry as a woman and cannot change her birth certificate to reflect her true female sex.

Our pigeonholing of sex wasn't always so concrete, and in many cultures it still isn't. Some Native American cultures, for example, are perfectly at home with "two spirits", those who fall between our ideas of gender. They are left to mature happily into intersex adults. In Samoa the Fa'afafine are neither male nor female and are an integrated part of society.

Tanya Ni Mhuirthile, a law lecturer at University College Cork specialising in bioethics, explains how we, too, used to be happy with a more fluid idea of sex. "As far back as the 1600s an aristocrat called Lord Coke wrote about intersex people and referred to their right to be recognised as male or female of their choosing by law. But over time that visibility and the rights of intersex people in society slowly vanished."

She explains that once people moved from the countryside into cities in the industrial ➡

era, this change accelerated. "Country people were linked to nature. They knew that sexual variation occurs everywhere. Women were the only ones in the delivery room and no one was judging or counting. But that all changed once power shifted from the land to the gentry – and with the birth of factories, the labour force needed to be quantified. It became compulsory to register births, and there was a space for the baby's sex.

"Suddenly, there was no room for ambiguity. Our natural differences in genitalia became medicalised, an aberration to be 'normalised', and sex assignment became the norm. That's the point at which everything intersex went underground."

And it's remained there ever since, with children lied to about their true intersex birthright – their own medical histories kept hidden from them – or left to flounder through their adolescence, avoiding changing rooms, mortified by their own bodies, mystified by their apparent non-conformity. At least, that was the state of affairs until Greenberry co-founded Intersex UK (with the slogan "No Body Is Shameful").

"The procedures intersex babies and children are subjected to often result in permanent infertility, pain, incontinence, loss of sexual sensation and lifelong emotional suffering," says Greenberry. "The incredible thing is that whenever I tell anyone my story they react with utter horror and astonishment. They ask how this can be happening without them knowing, still going on in hospitals around the UK."

Greenberry has recently become the first intersex person to address the United Nations, which is now calling on all countries to "repeal any law allowing intrusive and irreversible treatments, including forced genital-normalising surgery, involuntary sterilisation, unethical experimentation, medical display, 'reparative therapies' or 'conversion therapies', when enforced or administered without the free and informed consent of the person concerned". At a recent two-day UN conference in Geneva to look at intersex rights, the high commissioner for human rights, Zeid Ra'ad Al Hussein, admitted he himself had known little beforehand. "Too many people assume, without really thinking about it, that everyone can be fitted into two distinct and mutually exclusive categories," he said. "But in fact human beings – like most living beings – are more diverse and complex than that."

So far Malta has led the way. As of April this year, intersex babies no longer undergo a clitoridectomy at birth on a clitoris deemed too large and penis-like, or are force-fed hormones to "turn them into a boy" despite having ovaries, or are castrated (90 per cent of intersex babies leave the operating theatre as girls after "normalising" surgery, on the grounds that it's much easier to take away than it is to add).

Dawn Vago

> 'WHY WASN'T I TOLD? WHY DID I GROW UP IN A WORLD OF SHADOW AND SHAME?'

In 2013 Germany became the first European country to pass a law allowing a birth certificate to be marked with an X "to take the pressure off parents to commit themselves to gender immediately after birth", according to the interior ministry.

So far the UK shows no signs of following suit. The Home Office says there are "no plans" to consider a gender neutral symbol on passports or birth certificates or for the latter to be left blank until a later date. There is one lone parliamentary voice calling for change – Lord Stevenson, who was born with hypospadias, in which the urinary opening is not in the usual location, a condition affecting some 1 in 300 boys (and some girls, but less noticeably and obviously), and a figure that, according to Great Ormond Street Hospital, is increasing for reasons not yet understood.

While hypospadias is often not included under the intersex umbrella of conditions (although many who have it do identify as intersex), Lord Stevenson understands only too well the shame and stigma that come from being differently formed. "There are resonances between my condition and intersex variations. For my whole adolescence and early adulthood I had to conceal my difference, the fact I wasn't the same as others. And it wasn't until I was in my thirties I realised I was not alone, that there were others like me and they also had difficulty forming relationships, doing normal things like getting undressed in a public changing room in case they are exposed. There are a lot more people around with intersex conditions than people realise – and there is a role for legislation. For instance, in debating the same-sex marriage bill, there wasn't a space for those yet to declare which sex they wish to be considered. It's also wrong that we operate on babies first and consider how that operation has affected them later. What sort of normality is it when a surgeon 'corrects' a penis because he has some sort of idea of what a perfect penis looks like? We are feeding intersex teens hormones and subjecting them to constant surgery. It's terrible. I've had letters with stories that have made we literally weep at what intersex people have been through."

This saddens Intersex UK co-founder Dawn Vago, who, like Greenberry, has fought hard to be proud of who she is. Vago, 35, lives in Warrington with her husband of ten years and works as a programme director and singer. She has complete androgen insensitivity syndrome, which meant that although she was born with apparently typical-looking female genitalia, she lacked the internal reproductive system of fallopian tubes, a womb and ovaries, and had internal testes. "I was told from a very early age I was 'different'. My parents agreed to my testes being removed because they were told that, if they didn't, I would develop cancer. This isn't true – the risk of cancer is lower than other female cancers in typical bodies, and with check-ups my body would in all likelihood have remained healthy. What we also weren't told was if they had left my testes inside me the testosterone would later convert to oestrogen. Poor medical advice led to osteoporosis and 11 broken bones due to the mismanagement of synthetic hormones I was given."

Vago was told no one else in the country had anything like this. "There were no support groups; there was no one that I could identify with. More importantly, there was no one for my parents to speak to.

"I was very lucky – my parents were full of love, openness, understanding and care. ➡

Unfortunately, I didn't receive the same care and attention from the medical profession, who held quite a bit back. I think the low point was when I was in my early teens and told my doctor, with elation, that I had a crush on a boy who liked me – I wanted to tell everyone. But she very quickly and nervously looked to another doctor and I was escorted into another room, where I was then put onto the table. Something was inserted into me and I was told this would have to be done on a regular basis as I had a shallow vagina. This affected me greatly – emotionally and intimately. It wasn't something I wanted to have done to me at the age of 14.

"This wasn't the first devastating moment I'd experienced with the medical profession. My parents had previously been told, 'No man will ever love her,' and instructed to push me into a career. Even though I'm married to the most amazing man, those words still circle around my head and I have to consciously shake them away."

> 'I'VE SAT WITH MUMS WHO ARE IN TEARS DEALING WITH WHAT THEIR CHILD IS FACING FROM THE MEDICAL PROFESSION'

Vago had some dark times but found support in her early twenties. "When I met other people like myself and I realised how many of us there are, it blew my mind. I was so happy, so, so unbelievably happy, but then that turned to anger. Why was I not told? Why had that been kept from me? Why were my parents not told this? Why did I grow up in a world of shadow and shame? It shouldn't have been like that and that's why I'm standing tall now."

However, there are some signs of intersex issues filtering into mainstream life in the same way that trans issues did before Caitlyn Jenner's celebrity transition brought them into the limelight. An MTV teen show, *Faking It*, features a character who happens to be intersex and the 2015 Rainbow List of the 101 most influential LGBTI personalities in Britain, published last month, included Vago and Greenberry at No 5, along with stand-up comic and fellow intersex advocate Sarah Graham at No 2. Lady Colin Campbell, who was born intersex, brought up as a boy named George and forced by her parents to have hormone therapy to keep her "male" as a teenager, made headlines recently in *I'm a Celebrity ... Get Me Out of Here!*.

President Obama notably hosted several prominent US intersex activists at the White House at the end of November to coincide with the US premiere of Eddie Redmayne's Oscar-tipped *The Danish Girl* (although intersex advocates are keen to emphasise the distinction between transgender and intersex issues).

A few young intersex adults in the US have banded together to create the hashtag Intersexy. One of them, Emily Quinn, has also acted as an adviser to the producers of *Faking It*, and has now started a YouTube channel, Intersexperiences, to speak frankly – and at times very humorously – about life as an intersex person. "I think I'm part of a new wave," she says. "It was a tough decision to put myself out there as openly intersex, but at the same time it was quite simple. If it helps anyone not be operated on without consent or feel less alone and confused, it's 100 per cent worth it. I was expecting a lot more abuse than I received and most people have been pretty wonderful. I think 'intersexy' is a great word for us to show the world that intersex people's bodies are sexy, too."

Since 2006 the NHS guidance has been that when an intersex baby is born, a whole team of experts should be brought in to support the parents medically and emotionally. The official policy is that there should be no rush or pressure to assign a newborn to either sex while the parents are helped to understand the complexities of their individual child's case, and that surgery is not the default option.

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INTERSEX: THE DIFFERENCES

Intersex is a group of conditions where there is a discrepancy between the external and internal genitals (the testes and ovaries). The older term, hermaphroditism, is now considered insensitive. Intersex differences can be divided into four broad categories.

46, XX INTERSEX

The chromosomes and ovaries are female, but external genitals appear male. This is usually the result of a female foetus having been exposed to excess male hormones before birth. The labia fuse and the clitoris enlarges to appear like a penis. Usually there is a working uterus and fallopian tubes. There are several possible causes, including: congenital adrenal hyperplasia; male hormones taken or encountered by the mother during pregnancy; male hormone-producing tumours in the mother (most often ovarian tumours); and aromatase deficiency (aromatase is an enzyme that converts male hormones to female hormones).

46, XY INTERSEX

The chromosomes are male, but the external genitals are incompletely formed, ambiguous, or clearly female. Internally, testes may be "normal", differently formed, or absent. There are a variety of possible causes. 1) Problems with the testes that produce male hormones. 2) Problems with testosterone formation. Each step of testosterone production requires a different enzyme – deficiencies in any of these can result in depressed testosterone levels. Different types of congenital adrenal hyperplasia can fall in this category. 3) Problems with using testosterone. Some people have "normal" male testes and make usual amounts of testosterone, but still have 46, XY intersex. 4) 5-alpha-reductase deficiency. People lack the enzyme to convert testosterone to dihydrotestosterone (DHT). There are at least five types of 5-alpha-reductase deficiency. Some have male genitalia, some female, and many have something in between. Most change to external male genitalia around the time of puberty. 5) Androgen insensitivity syndrome (AIS). This is the most common cause of 46, XY intersex: the receptors to male hormones don't function as in non-intersex people.

TRUE GONADAL INTERSEX

There is both ovarian and testicular tissue, possibly in the same gonad (an ovotestis), or there may be one ovary and one testis. The person may have XX chromosomes, XY chromosomes, or both. The external genitals may be ambiguous or may appear to be female or male. In most people with true gonadal intersex, the underlying cause is unknown, although in some animal studies it has been linked to exposure to common agricultural pesticides.

COMPLEX OR UNDETERMINED INTERSEX DISORDERS OF SEXUAL DEVELOPMENT

Many chromosome configurations other than simple 46, XX or 46, XY can result in disorders of sex development. These include 45, XO (only one X chromosome), and 47, XXY, 47, XXX – both cases have an extra sex chromosome (either an X or a Y). These disorders do not result in a condition where there is discrepancy between internal and external genitalia. However, there may be problems with sex hormone levels, overall sexual development and altered numbers of sex chromosomes. ■

But the whole issue of intersex babies and children appears to be highly controversial. Finding someone to talk officially about it is difficult, even off the record. One willing to talk openly is Professor Sarah Creighton, who counselled Suz Temko and is one of the leading specialists pushing for change in the treatment of intersex babies and young children. She co-wrote an excoriating (by medical standards) paper in *The BMJ* in late September called *Parental Choice on Normalising Cosmetic Genital Surgery*. In it she made it clear the 2006 official NHS "no surgery" guidelines were being treated with the same respect a toddler affords the idea of table manners.

According to Creighton, "Paediatricians have previously stated that the determining factor in deciding to raise a child as a boy is 'the size of the phallus'. Newborn penile size charts were used in the Sixties and any child with a penis of stretched length less than 2.5cm was likely to be assigned female regardless of the underlying diagnosis. Feminising genital surgery usually followed. Genital assignment has become less simplistic but normalising surgery remains common." She goes on to say that "the rate of female assigned and surgically feminised children who reassign as male" later in life is "of concern", and that, "An additional, non-surgical care protocol is required to enable parents to cope with what may feel like an insurmountable pressure to appear normal."

"In the UK," she notes, "genital surgery for children with atypical genitalia remains part of standard medical care," adding, "Given the increasingly adversarial atmosphere in this field, more of the same is not an option."

Holly Greenberry points to the case of separated parents Michelle and Kyle, in the news this month, who are in dispute as to whether their intersex son, Aubrey, who had feminising surgery but now wishes to be a boy, should be raised male or female. "This poor child has lost his genitals – these should be his for life. Why are doctors ignoring these mistakes? My own experience of offering support to parents on the front line is that 'non-surgical' alternatives simply aren't what's happening. I've sat with mums with tears rolling down their faces, trying to deal with what they and their child are facing from the medical profession. There is still a benchmark cut-off point where there's an atypicality of genitalia – and scalpels are seen as the answer."

She argues that there is not a single record of any infant having died as a direct result of having either a clitoris larger than 9cm or a penis smaller than 2.4cm. "Surgery is intersex genital mutilation, IGM, and no different from FGM. Scalpels don't sculpt gender; they sever futures."

STYLING: FRANCESCA MULLIN. HAIR: ENZO VOLPE AT MANDY COAKLEY REPRESENTS USING DIVA PRO HAIR. MAKE-UP: LAUREN ALICE USING BOBBI BROWN. DAWN WEARS (PAGE 28) SHOES, CASADEI.COM, AND (PAGE 33) DRESS, SIMPLYBE.CO.UK. SUZ WEARS (PAGE 29) DRESS, STORIES.COM, SHOES, GIANVITO ROSSI, AND (PAGE 36) TOP, THEORY.COM, TROUSERS, SAMSOE.COM. HOLLY WEARS (PAGE 31) BUSTIER, ADINAREAY.COM, SHOES, LONGTALLSALLY.COM

Suz Temko

'SOMETHING IS CHANGING. MORE OPEN ATTITUDES AND MINDS… IT'S EXCITING'

But Dr Joe Brierley, chair of the ethics and law advisory committee at the Royal College of Paediatrics and Child Health, argues that it is often parents who are driving gender assignments.

"Sometimes it's the child's family who say, 'We don't want them going to school looking like that – what will happen in the changing rooms?' They are the ones suggesting 'normalising' surgery, despite medical teams urging them to hold off, hence the need for expert multi-disciplinary support. As far as I know, this type of surgery no longer happens in infants, though I am unaware of any UK or international register of procedures."

Ieuan Hughes, a paediatrics professor at the University of Cambridge, offers a different perspective. "Is it really desirable and indeed, practical, to ignore the accepted practice of mankind's binary sex and raise an infant born with indeterminate sex, aka intersex, as a third sex?" he argues. "How would the parents of such an infant cope with that idea? To my knowledge, nobody in the UK has followed that practice and it certainly is not recommended by specialist clinics that care for families who find themselves in this challenging situation. It is recommended that intersex infants should be gender assigned (female or male), although the decision may take a number of weeks pending the results of investigations, some of which may be complex. But delaying an assignment so that the sex remains indeterminate until the child has sufficient cognitive development to engage in the decision-making is not on the agenda. What is paramount is the importance of teamwork among professionals when supporting a family with an intersex child."

In October, Greenberry, Vago and Temko went to Plymouth University to give a talk to the medical students and staff. A no-holds-barred Q&A session took place afterwards. "Basically, the students' jaws dropped," says Greenberry. "They couldn't believe we'd stood everything they thought they knew about biological sex and gender and 'abnormalities' on its head."

Dr Siobhan Moyes, the lead for anatomy teaching at the university, says she has changed the way she lectures as a result. "The students were incredibly receptive and it was an epiphany for me, a major shift in my mentality. I've stopped talking about 'abnormalities' and talk about 'differences'. I now tell students it's perfectly normal to have different genitalia, different courses of nerves or different sized sex organs. Everyone is unique. I could probably count on a very small abacus the number of completely average people in the population."

Intersex UK now plans to hold further talks with other medical schools to teach the next generation of doctors that there are many healthy, natural shades between pink and blue. "Something is changing," says Temko, who now has a policy of being open about herself with work colleagues, boyfriends and friends, and also blogs about all things intersex at XYSuZ. "Gender fluidity, more open attitudes and open minds – the conversation has changed so much, and the idea that 'no body is shameful' actually seems to be becoming real. It's exciting." ■

Intersex UK is campaigning for: 1) All sex and gender categories to be removed from birth certificates and identification documents, in the same way race and religion are not mentioned. 2) To raise awareness of, and secure rights and anti-discrimination laws for, intersex people. 3) For full information about someone's medical records and history to be disclosed before medical intervention. 4) For the provision of all human rights, legal and citizenship rights, including the right to marry and form a family. For further information, go to intersexuk.org; interfaceproject.org