The extraordinary case of the Guevedoces

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The discovery of a small community in the Dominican Republic, where some males are born looking like girls and only grow penises at puberty, has led to the development of a blockbuster drug that has helped millions of people, writes Michael Mosley.

Johnny lives in a small town in the Dominican Republic where he, and others like him, are known as "Guevedoces", which effectively translates as "penis at twelve".

We came across Johnny when we were filming for a new BBC Two series Countdown to Life, which looks at how we develop in the womb and how those changes, normal and abnormal, impact us later in life.

Like the other Guevedoces, Johnny was brought up as a girl because he had no visible testes or penis and what appeared to be a vagina. It is only when he approached puberty that his penis grew and testicles descended.

Johnny, once known as Felicita, remembers going to school in a little red dress, though he says he was never happy doing girl things.

"I never liked to dress as a girl and when they bought me toys for girls I never bothered playing with them - when I saw a group of boys I would stop to play ball with them."

When he became obviously male he was taunted at school, and responded with his fists.

"They used to say I was a devil, nasty things, bad words and I had no choice but to fight them because they were crossing the line."

We also filmed with Carla, who at the age of seven is on the brink of changing into Carlos. His mother has seen the change coming for quite a while.

"When she turned five I noticed that whenever she saw one of her male friends she wanted to fight with him. Her muscles and chest began growing. You could see she was going to be a boy. I love her however she is. Girl or boy, it makes no difference."

So why does it happen? Well, one of the first people to study this unusual condition was Dr Julianne Imperato-McGinley, from Cornell Medical College in New York. In the 1970s she made her way to this remote part of the Dominican Republic, drawn by extraordinary reports of girls turning into boys.

When she got there she found the rumours were true. She did lots of studies on the Guevedoces (including what must have been rather painful biopsies of their testicles) before finally unravelling the mystery of what was going on.