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# Down

## Chromosome 21

# Syndrome

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Day

March 21

## WHERE ARE THE PARENTS?

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The following was written by a mother of a special child in response to a question asked by a school official as to why there weren't more parents of special needs children active in helping with the PTA. The official sent her a message, "Where are the parents?" The mother wrote this essay and distributed it to the entire PTA!

## WHERE ARE THE PARENTS?

...They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed.

...They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

WHERE ARE THE PARENTS? ...They are at home, diapering their 15 year old son, or trying to lift their 100 lb. daughter onto the toilet.

...They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube.

...They are administering medications, changing catheters and switching oxygen tanks.

WHERE ARE THE PARENTS? ...They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for test results to come back and wondering if their child will pull through.

...They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ.

...They are waiting in long lines in county clinics because no insurance company will touch their child.

WHERE ARE THE PARENTS? ...They are sleeping in shifts because their child won't sleep more than two or three hours a night, and must be constantly watched, lest he do himself, or another member of the family harm.

...They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cutbacks of their own.

WHERE ARE THE PARENTS? ...They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive.

...They are struggling to keep a marriage together, because adversity does not always bring you closer.

...They are working 2 and sometimes 3 jobs in order to keep up with the extra expenses. And sometimes they are a single parent trying to do it all by themselves. WHERE ARE THE PARENTS?

...They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything.

...They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families.

They are busy, trying to survive...

# How Emma managed to get in on the act

<http://www.telegraph.co.uk/health/main.jhtml?xml=/health/2002/12/02/hdown02.xml>  
Last Updated: 12:01am GMT /12/2002

## **Emma Hill was as determined as her mother not to let Down's syndrome prevent her from becoming an actress. Ann McFerran reports**

For Susan, the most difficult times have been their encounters with members of the health service. "They paint aOn the second day of the most exciting week of her life, Emma Hill was brutally murdered. Her wrists were bound tightly with sharp wire; her throat was cut and she was strung up by her arms and tied to a swing.



**Chicken Shed Theatre:  
where Emma discovered  
her love of acting**

"My neck was really gross," says Emma. "But the worst bit was when the make-up people poured two huge canisters of Pigs Might Fly blood all over me. The blood was sticky and disgusting. After I'd hung there for a bit, I told them I really was dying: it was February and I was freezing cold. Fortunately, I didn't have to play dead for too long."

Emma, an 18-year-old actress, is still recovering from the excitement of her first television role, as Alun Armstrong's screen daughter in the BBC's forthcoming film noir-ish thriller *Messiah 2: Vengeance is Mine*. Emma has Down's syndrome, which is unusual for an actress. But Emma is unusual in many ways. "I'm not quite sure what Down's syndrome means," she says. "I mean, I know I've got Down's syndrome, but I don't like having it, because it makes me feel different from everyone else."

"Down's syndrome is a label that has determined Emma's life," says her mother, Susan. "But she hates it. She wants most of all to be an actress and to be beautiful, and she thinks that having Down's syndrome is stopping her."

Susan and Emma are sitting, sipping Diet Cokes, at the Chicken Shed in north London, the theatre centre for young people of all ranges of ability.

It was to the Chicken Shed that Susan went, in desperation, in search of an activity that her young daughter would be

able to enjoy on her own. For Susan, it was important that Emma developed her own sense of independence, just like her two older sisters, Kathryn and Nathalie. But no swimming class, gym group or Brownie pack would take Emma unless her mother accompanied her. At the Chicken Shed, Emma revealed herself to be an outstanding young talent, and has since performed with the Spice Girls, Meat Loaf and Cliff Richard.

"The be-all and end-all in Emma's life is acting," says Susan. "She's so determined to be an actress that she has stolen stamps from my purse so she can write letters to the producers of EastEnders, Friends and Byker Grove."

A year ago, Emma auditioned for a part in The Bill, but the director, David Richards, told her she was too individual to play a stereotypical Down's syndrome girl. Several months later, he called to say he'd found the right part for her.

The day Emma was filmed being stalked and murdered was the longest in the shooting schedule. Although she was tired after her 6am start, it was Emma who stopped the filming when she saw "I had blood spattered all over my shoes, and I hadn't died yet". Continuity had not noticed, and nor had the director.

"Emma is really clever," says Richards. "That's one reason I wanted her for the part. She's also absolutely right for the role. There's nothing in the script to indicate that her

character has Down's syndrome, but I don't see why we should play to blind prejudice."

When Susan first became pregnant with Emma, she recalls seeing children with Down's syndrome wherever she went. "It felt as though they were singling me out," she says.

She was worried that she might be carrying a baby with the condition, and went to her local health centre for a scan. Early in pregnancy, a baby with Down's syndrome has a smaller than average head, but the nurse told Susan her baby's head was a perfect size and she had nothing to worry about.

When, six months later, the midwife placed Susan's tiny daughter in her arms, she recoiled in horror. "This baby was ugly," she says. "My first two were beautiful babies. I thought: 'This isn't one of mine'." The only thing that Susan knew about children with Down's syndrome is that she didn't want to have one. But she reckoned without the determination of newborn Emma. Contrary to the expectations of Down's syndrome babies, Emma breast-fed immediately and hungrily. But Susan felt she wasn't able to deal with the strain of having a Down's baby, and decided to abandon her. A few days after she'd left Emma at the hospital, her sisters demanded to meet her.

As they arrived on the ward, Susan heard Emma cry. She was refusing to take a bottle, and Susan went over to her baby's cot, picked her up and fed her.

"And that was it," she says, "I carried her home, thinking that it would be just for one day. But that was 18 years ago, and she's taught me more in that time than I've ever learnt before." very negative picture of a Down's child like Emma."

Doctors warned Susan that Emma would smile, crawl, talk and walk later than other children. But she developed at exactly the right rate.

Once, Susan seized an opportunity to glance at Emma's medical records. The hospital doctor had written that Susan was refusing to accept that her child had Down's syndrome. In fact, Susan was refusing to allow her daughter to be discriminated against, or have fewer opportunities than her sisters.

When Emma first went to school, she wasn't given a tin of words to learn like the other children, and when Susan protested, she was given only seven words. Yet, by the age of five, she had learnt to read.

"Often, the teachers separated me from the other children because I have Down's syndrome, which made me feel different," Emma says. "But I wanted to be popular and have lots of friends. When you're a teenage girl, you especially don't want Down's."

Emma says that appearing in Messiah made her feel special. Her favourite days were when she played opposite her

screen boyfriend. For those scenes, the make-up lady and wardrobe department helped her to look her best.

"I looked in the mirror after they'd done my hair and my make-up and I thought: 'Even though I've got Down's syndrome, I look beautiful'."



# One chromosome makes all the difference

## What is Down's syndrome?

Chromosomes determine all of our body's characteristics. Down's syndrome is a genetic condition caused by the presence of an extra chromosome. Instead of having the usual 46 chromosomes (23 pairs) in each cell, a person with Down's syndrome has 47 because he or she has three copies of Chromosome 21.

Forty to 50 per cent of babies with Down's syndrome are born with congenital heart disease and intestinal defects. Life expectancy is estimated at around 60 years.

## How many people are affected?

One in 1,000 babies born in Britain have Down's syndrome. The risk of a woman giving birth to a Down's syndrome baby increases as she gets older.

## How can a pregnant woman have her baby tested for Down's?

[Commonly, all expectant mothers are offered screening](#), usually with a blood test, from 14 weeks of pregnancy. The level of specific substances in the blood is measured, and the results are combined with a woman's age at her expected date of delivery to give an estimated level of risk.

Only older mothers and those considered to be at high risk after this test are then offered amniocentesis at 15-16 weeks of pregnancy. This involves inserting a fine needle into the womb to remove a small amount of amniotic fluid surrounding the baby. The number of chromosomes is examined. The procedure carries a small risk of miscarriage.

Recently, a new method of screening called Nuchal Translucency Scanning has been developed. This is an ultrasound scan that is carried out between 10 and 13 weeks of pregnancy to measure the depth of fluid at the back of a baby's neck. The deeper the space, the greater the risk of Down's syndrome. But this test only estimates the chance of a baby having Down's syndrome.

Catalina Stogdon

