

## Why?

Many parents worry that something they did caused idic 15. This is never true. Although this may be hard to accept, idic 15 and most other rare chromosome disorders occur by chance. Nothing you did caused it and there was nothing you could have done to prevent it, either.

## Can it happen again?

The type of idic 15 described in this leaflet almost always happens out of the blue (de novo). This can be shown by tests of the parents' chromosomes and in this case, your chances of having another baby affected by idic 15 are no higher than anyone else's.

The type of small SMC15 that causes no difficulties and therefore often goes undetected does run in families. As every family is unique, you should discuss your individual situation with a geneticist or a genetic counsellor.

## Other types of idic 15

This leaflet describes the most common type of idic 15. These are some less common types.

- Some people have some cells with the extra chromosome and others without. This is called mosaicism and usually lessens the impact of idic 15.
- A very few people have more than two extra copies of the bit from the top end of chromosome 15. As you would expect, their symptoms are more severe.
- In some people, the extra segments do not form a separate chromosome. Instead they are added into one of the two other chromosome 15s, making it a slightly longer chromosome. The effects on the child are just the same as if it was a separate chromosome.
- Some people have a much smaller additional chromosome that does not appear to cause problems. This type of small SMC15 does not contain a particular segment that lies between bands q11 and q13. It is the extra copies of this segment that cause the clinical difficulties in children with idic 15.

## Families say ...

- ... *His love of music is very special. He knows many tunes, picks them up well and 'sings' them. He can be very exact and it is a delight to listen to him - age 7.*
- ... *A lovely, slightly dreamy girl with a happy disposition - age 10.*

*Unique*

For support,  
contact with other families and information

**Rare Chromosome Disorder  
Support Group**

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**info@rarechromo.org**

**www.rarechromo.org**

**IDEAS**

**www.idic15.org**

*Unique* mentions other organisations' message boards and websites to help families looking for information. This does not imply that we endorse their content or have any responsibility for it.

When you are ready for more information, *Unique* can help. We can answer individual queries and we also publish a full leaflet about the effects of Idic 15.

This information sheet is not a substitute for personal medical advice. Families should consult a medically qualified clinician in all matters relating to genetic diagnosis, management and health. The information is believed to be the best available at the time of publication and the medical content has been verified by Dr Nick Dennis, Clinical Geneticist, Wessex Clinical Genetics Service, and by *Unique's* Chief Medical Adviser 2004.

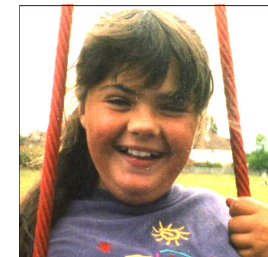
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Charity Number 1110661  
Company Number 5460413

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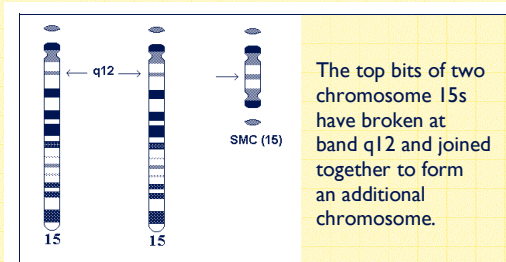
# Idic 15



Also available in French

## What is Idic 15?

Idic 15 is a very rare chromosome disorder where people have too much genetic material, usually in every cell in their body. In addition to the 46 chromosomes that everyone has, they have a small additional chromosome which is derived from chromosome 15. Chromosomes come in pairs, and the two normal chromosome 15s are present. The additional chromosome usually consists of two copies of the bit right at the top end of chromosome 15 joined end-to-end in mirror image.



**Idic 15** is also called **SMC 15**. Idic 15 stands for **I**sodicentric **15** and SMC 15 means **S**upernumerary **M**arker **C**hromosome **15**. Another name for idic 15 is inv dup 15 (**I**nverted **D**uplication 15).

Most children are healthy and grow and look just like other children. This can mean that diagnosis is delayed because doctors often expect children with chromosome abnormalities to look unusual.

### Common features

The impact of idic 15 is hard to predict in a young child.

- **Unusual social responses**
- **Unusual behaviour**
- **Muscles that in babies may feel 'floppy'**
- **Delay in reaching baby 'milestones'**
- **Delay in starting to speak**
- **Learning difficulties**

The

severity of problems is quite variable, but it is not yet known why. As with any child, the environment and the whole genetic make-up must be important, not just the idic 15.

## Development

### Behaviour

Children can behave in ways that are in sharp contrast to their otherwise sweet, affectionate and sometimes anxious nature. Many babies are placid and a few children remain reserved. But most have outbursts when they are challenging, noisy, overactive and sometimes destructive. Firm routines, behaviour management training and certain prescribed medicines are all helpful.

### Social responses

Social cues often don't elicit a response in babies and young children. Most babies smile late and they may not seek normal eye contact. In younger children other features typical of autism (stereotyped behaviour, difficulties with changes in routine) are also common. Both social responsiveness and autistic features improve with age but a tendency to avoid social interaction remains.

### Learning

Most children need considerable help with learning. They are usually late to start talking, saying their first words on average around 27 months. While most progress to speaking in short sentences and holding simple conversations, a small minority do not talk.

### Physical development

Children are slightly late in learning to roll over and sit and they take their first steps on average one or two months before their second birthday. Although some clumsiness persists, many children eventually learn to run, dance, skip, cycle, swim and play organised sports.

## How common is idic 15?

Idic 15 is one of the commoner rare chromosome disorders. It's believed to affect around 18 babies in every 100,000. This means that 100 babies are born with it every year in the UK, 720 babies in the US and 45 babies in Australia. If that sounds a lot, it is actually so uncommon that most doctors and paediatricians have never met an affected child before. But *Unique* and other chromosome support groups know many families with idic 15 and as well as providing information and support can put them in touch with each other.

## Medical conditions

- **Neonatal** Although some mothers succeed in breastfeeding, about half the babies have feeding problems. These are often caused by weak sucking, difficulty co-ordinating sucking with swallowing or by reflux. This is an extreme form of possetting where milk and stomach secretions flush up the food pipe. Careful positioning, thickeners and antacid medicines usually control reflux.
- **Seizures** Half to two-thirds of children will experience seizures of different types and starting at different ages. In some children seizures start near the onset of puberty or early adolescence. In general, children who are more severely affected tend to develop seizures, but this will not be true for everyone.
- **Frequent infections** Around half of children have frequent ear or respiratory infections and half of these children need grommets or T-tubes to improve their hearing.
- **Strabismus** Strabismus (squint) occurs in almost 40 per cent of children. However, in most it resolves with age and without surgery.
- **Feeding** In mid-childhood a small number of children develop a tendency to overeat, cramming their mouths without appetite control.
- **Puberty** For girls, puberty occasionally does not run smoothly. Premature puberty (at age 8) has occurred, while other girls have had started their periods but then had years of scant or no periods.
- **Occasional problems** Most children with idic 15 are born healthy but some have had hernias, hypospadias (where the hole for urine is under the penis, talipes (club foot), cleft lip or palate or have developed a spinal curvature.

