



Celine Rose Johnston

The story so far

Celine Rose Johnston

www.kinrara.net/celine.htm

LAST UPDATED 13th June 2004 - see NEW LINKS from page 19

Celine made her appearance at 1:58pm 12th Dec 2001.
Delivered by caesarean and weighing in at 2.2kg / 5lb.

BRAND NEW BABY



Shortly after starting to encourage the natural labouring process, as baby was monitored the pulse rate dropped from 120 to 82 during contractions.

It was thought best to prepare for theatre, as the stress of labour would be too much for baby. Things for theatre preparation happened very quickly, and within 1/2 hour from entering theatre baby was born and 1/2 hour later moved into recovery area.

It was discovered that the cord was tangled around baby's head so normal labour would have been very risky

MOTHER ORGANISING BABY



It will be a few days before they are allowed home, as baby is not yet feeding freely. Mostly through tube.

CELINE and BEAR Christmas 2001



There are some other issues with baby's heart and chromosomes that they will be doing tests on to determine any treatments etc.
For the heart it would at this stage be surgery at Greenlane hospital in 3 - 5 months.
To a new parent of a child who has Down syndrome the news that the child has a 40% chance of having a heart defect may come as the last straw.



P.S. Baby and Fiona came home 1/1/2002

There are 2 diagnosed conditions.

1. PDA

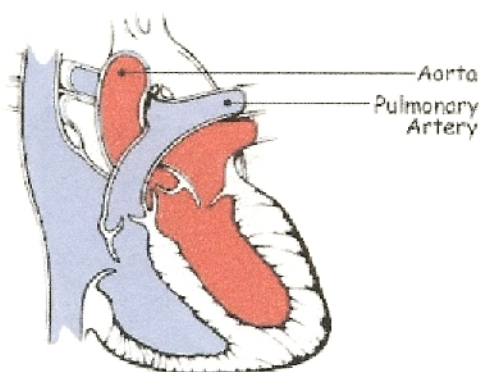
What is the ductus arteriosus?

The ductus arteriosus is a wide muscular blood vessel joining the pulmonary artery (main artery to the lungs) to the aorta (main artery to the body). This connection allows blood to be diverted from the lungs into the aorta during fetal development since the baby does not breathe until after delivery. The ductus arteriosus normally closes after birth. If it fails to close, PDA (patent or open ductus arteriosus) occurs and blood continues to flow from the aorta to the pulmonary artery. The effects of this altered circulation are:

Increased work of breathing
increased workload on the heart
fluid in the lung
right heart enlargement
increased lung workload

PATENT DUCTUS ARTERIOSUS (PDA)

NORMAL



DEFECT

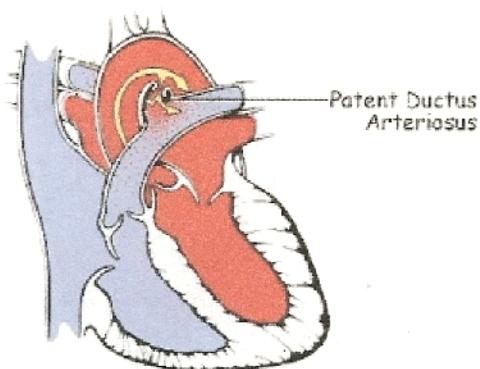


Diagram of the normal heart: blood flows from the left ventricle, into the aorta, and then out to the rest of the body.

Diagram of a heart with a PDA (patent ductus arteriosus): blood flows from the left ventricle, into the aorta, and then into the pulmonary artery (instead of going to the body where it is needed).

How is a PDA (patent ductus arteriosus) treated?

In small or premature babies, medicine may be used first to try to close the ductus arteriosus. In some cases medicine does not work or cannot be used and the ductus arteriosus must be closed surgically. Surgical correction includes closure of the PDA through a left thoracotomy incision (left underarm). The ductus is closed with a clip or is tied shut. In older children, medical treatment does not work. The ductus can be closed surgically or, in some children, a device placed through the artery into the ductus can be used.

GOOD NEWS

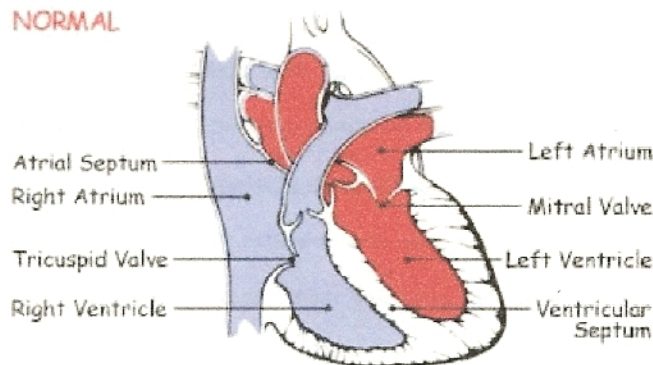
On 29th January our Doctor gave us the results of tests carried out a few days before. The ductus arteriosus has now closed off.

April 5th still needed some surgery to completely close this off.

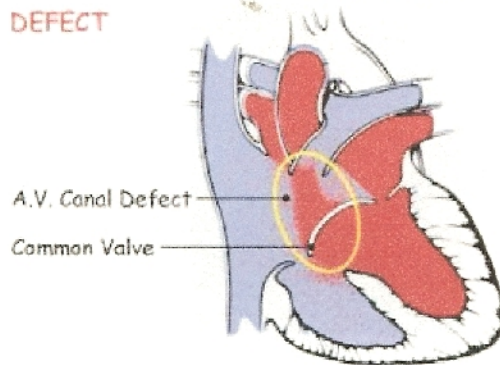
2. ACD

ATRIOVENTRICULAR CANAL DEFECT (Endocardial Cushion Defect, Atrioventricular Septal Defect)

NORMAL



DEFECT



Atrioventricular Canal Defect (Common Atrioventricular Canal) (CAVC) (Endocardial Cushion Defect)(ECD)

Clinical Presentation:

Is the most common congenital heart disease lesion in patients with Downs, as 25% of Down's kids have an ECD.

Etiology/Pathophysiology:

The endocardial cushions form the lower atrial septum, the upper ventricular septum, the septal leaflet of the tricuspid valve and the anterior leaflet of the mitral valve. An ECD defect is due to abnormal development of these endocardial cushions.

In a **complete ECD** there is a single confluent atrioventricular orifice between the anterior leaflet of the mitral valve and the septal leaflet of the tricuspid valve with fusion of the valve segments into a common valve across this orifice and a deficient base of the diaphragmatic wall of the ventricle. The ASD is usually large and the left to right shunt is regulated by the diastolic distensibility of the right ventricle. The right atrium receives blood from the left ventricle through an incomplete mitral valve and ASD while the right ventricle receives blood via an incomplete tricuspid valve. This leads to volume overload of the right heart leading to dilation of the right atrium, right ventricle, and pulmonary artery. The VSD and mitral regurgitation lead to left ventricle volume overload.

Partial ECD is more common than complete ECD and has an ostium primum ASD, a cleft anterior leaflet of the mitral valve, separate atrioventricular valves attached to the crest of a defective ventricular septum, and a variable occurrence of cleft septal leaflet of the tricuspid

valve. With a large ASD the cleft mitral valve results in right heart dilation with minimal left heart effects. With a small ASD the effects of the cleft mitral valve are borne by the left heart.

Update 29th January 2002

* See (patent ductus arteriosus) above

Update 28th February 2002

Celine weight 8lb, Surgery sheduled for 1st week in April.

Update 31st March 2002

Celine Weight 9lb, Admit to Greenlane Hospital Tuesday 2nd April

Surgery scheduled for Thursday 4th April



Update 4th April 2002



Greenlane Hospital ward 9 floor 6 top of largest building in background



Ultrasound scan showing heart with hole area

Because of 2 urgent cases that have been scheduled for today we have had Celine's surgery rescheduled for Friday 5th April.

Update 5th April 2002



Baby scrubbed down before operation 6:55am



Baby dressed in theatre fashion



Smiling happily all set for a big morning at 7:30am in spite of having no feed since 10pm Thursday 5th.



Baby's cot theatre equipped.



Baby asleep in mum's arms when theatre nurses take Celine for operation 8:15am



1:30pm Baby back to ICU (Intensive Care Unit) under sedation and on ventilator

Update 6th April 2002



9:30am reassuring baby things ok after coming off respirator



Familiar voice and touch



Having morning tea by tube (20mls off mum)



2pm baby back in ward with monitor



3pm as well as tube, having some feed off mum



Certificate well done.

Update 7th April 2002



Had a peaceful night's sleep



With only a few wires and tubes Visit to see auntie Celine from left. A little congestion in the lungs Grandson Jordan



Main dressing on chest removed mid afternoon.



Some water on a sponge to moisten dried lips. Still a little oxygen supplemented and medication to assist draining the lungs

Update 8th April 2002



Oxygen hose removed from nose overnight and bear holding a fasemask for Celine



Baby more settled for feed.



Update 9th April 2002



Baby organising her day, IV line in right hand, talking on her mobile phone with her new horse (any suggestions for the horses name?)



Preparing to pull out pacing wires that are attached directly to the heart.



Wires pulled out and cleaning the wound



Another echo to see that everything is ok after the wires are removed.

Update 10th April 2002



Baby sitting up ready to leave hospital



No, not Shortland street but, ward 9



Examination and obs of patient Ted E. Bear



A second opinion to check pulse and info posted



Hospital setting beneath One Tree Hill



and the view back



Wonderful hosting of Heart House for families of out of city patients during their time of treatment.



Update 11th April 2002

Returned home. A big thankyou to all who who have been involved in any way.

We had done some research in December 2001 after the birth of our daughter Celine, who has Downs Syndrome.

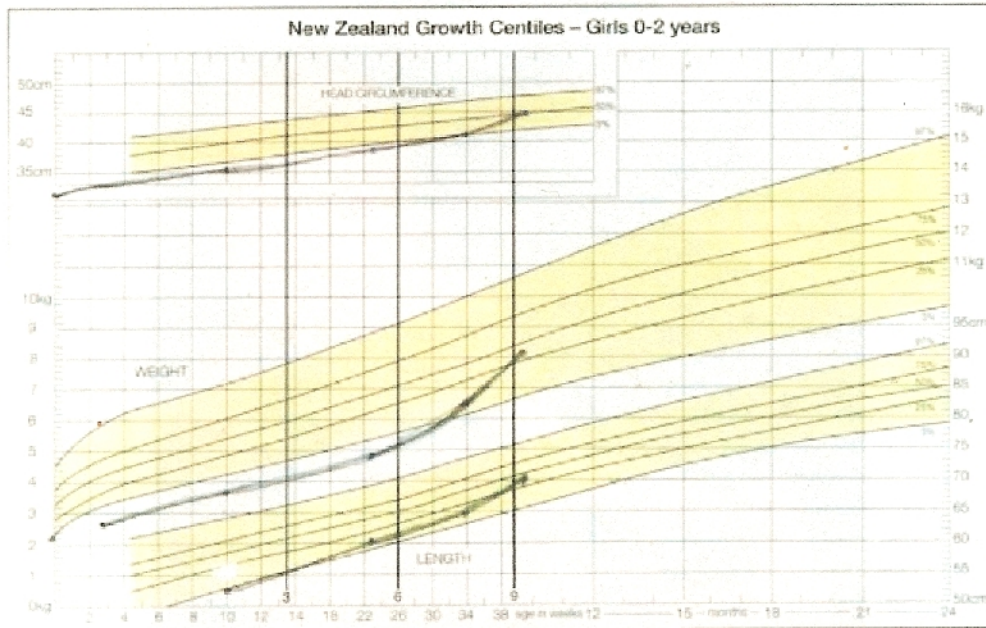
We found some information on Targeted Nutritional Intervention in the USA which was providing help for Downs children.

In June of this year 2002 some friends gave us information on the Mannatech range of products and we began giving baby some. This was started the first week in July at 29 weeks [1/3 tsp Ambrotose powder 2 x a day and 3/4 capsule Phyt Aloe 2 x a day mixed with solids. Added 1 sports capsule per day to this schedule at around 38 weeks. Also 1 capsule of mannaC per day now]

Other friends first made comments a few days later with, "there is something different about Celine", and they could see she was more alert and brighter eyed than she had been. Within a few days we began to notice that her joints were much stronger and now is standing for longer periods of time at 8 months. Prior to this although very active with legs was very floppy in the joints which we understand is because of another problem relating to Chromosome 21, a collagen deficiency that causes many Downs Syndrome children to be born with extreme, joint laxity. Celine continues to show spontaneity in her interactions with new talk sounds emerging.

Update 3rd October 2002

Graphs for girls



GROWTH GRAPH at 42 weeks (9.7 Months) for Celine Rose Johnston

Had heart operation at 16 weeks (4 Months)

Started Glyconutrients at 29 weeks (6.7 months)



Celine gardening with mum at 44 weeks

Update 26th October 2002



Auntie Celine and her 2yr old nephew 26th October 2002

Update 12th December 2002



Celine's 1st birthday the 12th of the 12th 2002 and she's healthy and developing well.

She has a very expressive personality, quick and spontaneous, loves to play games, clapping, etc. She enjoys an audience and likes to be busy - entertaining herself more these days, so mum is beginning to get some more things done. At 14 months she is moving around the floor by whatever means she can, on her bike, her tummy, rolling and more recently her knees. Nothing is safe from her little hands. She is very strong and firm. We are able to enjoy a very normally behaved little girl who doesn't suffer from the usual child coughs and flu's.

She is now having: - 2tsp of Ambrotose daily - 2 Phytaloe capsules daily - 2 Sports capsules daily - 2 Plus capsules daily

At any onset of coughs or nasal congestion, which is seldom, we add Manna C which works well. It was observed when we removed the sports capsule from her diet that she had lowered strength and muscle control.

Update 20th March 2003



Taken for a ride by horse in Texas



Meeting the Mouse ----- Outside his house inspecting his car

Update 26th April 2003



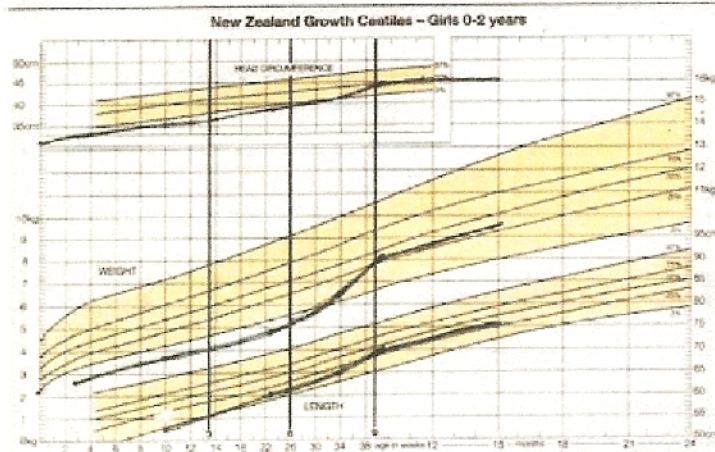
Celine explaining "It was this big" ----- Celine directing



Celine's Uncle Graeme trains horses - It's Celine's turn at the reigns

Some teeth have been surfacing in Celines mouth this past week

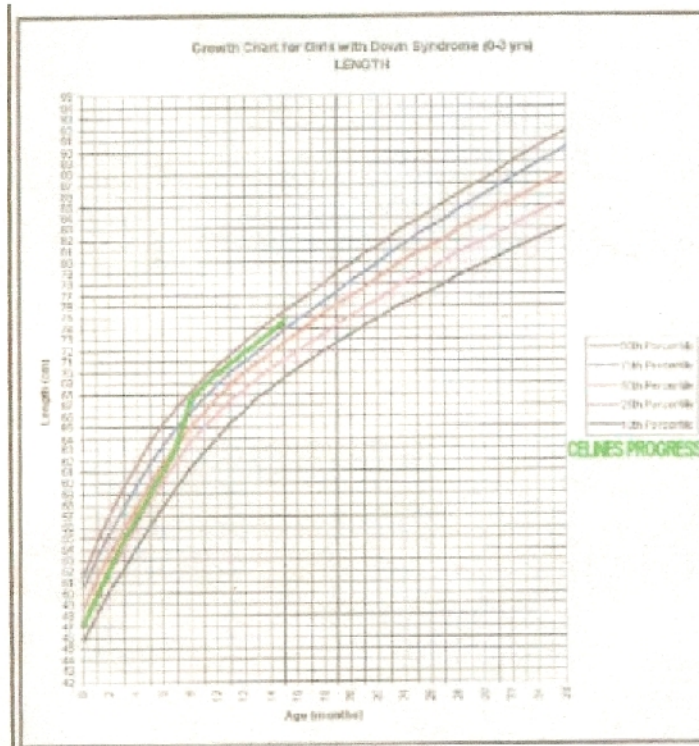
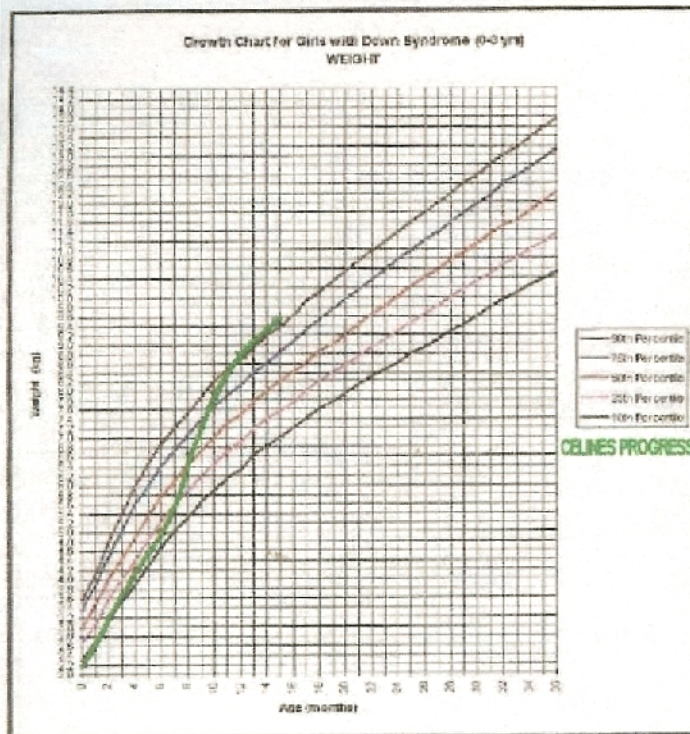
Graphs for girls

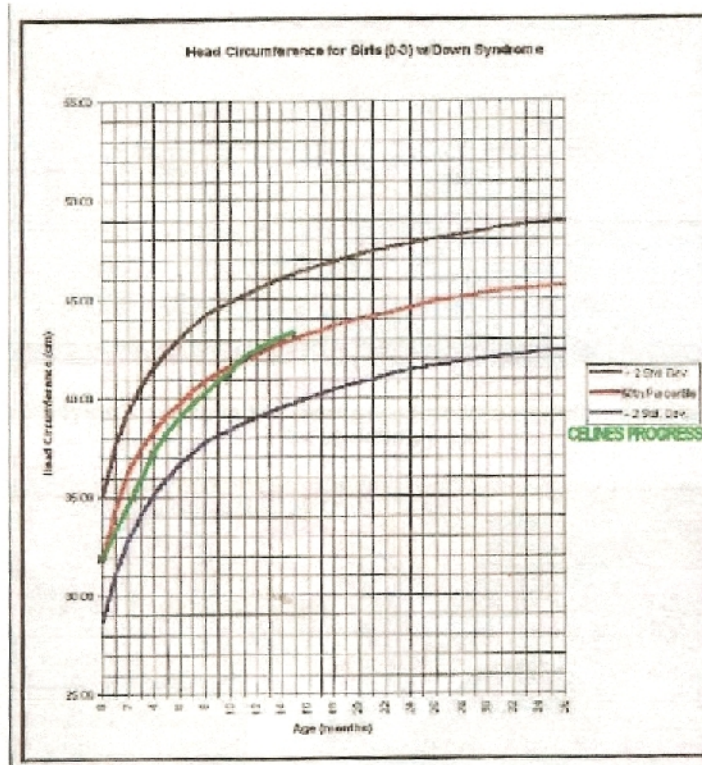


GROWTH GRAPH at 15 months for Celine Rose Johnston

Had heart operation at 16 weeks (4 months)

Started Glyconutrients at 29 weeks (6.7 months)





Throwing the Beach ball
- 3 December 2003



Kicking the Beach ball



Watching the Beach ball go down the steps



At 24 months Celine loves the opportunity to get the beat going on a drum kit



Christmas day 2003 - enjoying a swing in the hammock and conversation with an uncle - later a cool off in the paddling pool



The excitement of unwrapping and trying on some of the Christmas presents with the wider family



New Year's day 2004 - At the beach with Grandad - playing in a nice warm rock pool



Sand castles to make and adjust



At 25 months - Is the world ready for another driver? - With 3 1/2 yr old nephew - It is important to have plenty of practise.

Celine continues to develop well and maintain good health. She has a good number of teeth and a great appetite to match. The hand - eye co-ordination is good with drumming skills and will stack blocks and similar objects. Celine is currently using about 10 understandable words and some other phrases with gestures that family can translate. She is learning to feed herself although this is a longer operation for parents in a hurry. She loves to copy the big people and would prefer to sit at the table with them. Celine loves to connect with people and interact, sometimes she goes straight to it, and sometimes there is a warming up period. Potty training - we have had some successes and sometimes she just wants somewhere to sit. Many times she will pull out the potty before getting ready for bed. She is steady on her feet and can move fast when she wants, enjoying exploring her world.



Celine & Grandad stacking cups - Celine & Mum at work in the studio