Austprem

AT A GLANCE

Austprem Inc. is a major national self-help Internet based support group which now has well over 600 members!

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Volume 5 Issue 2

Premature birth, babies and beyond

When Your Baby Stops Growing Before Birth

store

ur pregnancy seemed to be a relatively easy one. I had some problems with high blood pressure but I put this down to the stress of my father-in-law having a heat attack, our buying a house at action and moving at Christmas time, and finishing up work in late December. I had no idea that our baby had stopped growing until I went to a check-up at Canterbury Hospital where it was revealed that my blood pressure had basically hit the roof with a reading of 150/100. An initial ultrasound indicated that the baby had extremely small limbs and was sitting on the 10th percentile. A tertiary ultrasound four days later at RPA revealed that our baby was even smaller than first thought and was measured on the 3rd percentile. This was explained to me in terms of babies lined up. I was told that if there were 100 babies lined up, ours would be the third smallest. Simply put, our baby had IUGR.



Thomas Devine was born at 28 weeks and weighed just 734g. He is 2 years old now. He is small in stature but not spirit!

Intrauterine growth restriction (IUGR for short) is a term used to describe a condition in which the fetus is smaller than expected for the number of weeks of pregnancy. The baby is not growing inside the uterus at the normal rate. These babies usually have a low birth weight. Another term for IUGR is fetal growth restriction. Newborn babies with IUGR are often described as small for gestational age (SGA).

This issue of *Austprem Ink* explores IUGR—intrauterine growth restriction: its causes, diagnosis and management. Jodi Devine

The baby is not growing inside the uterus at the normal rate.

Small Baby Definition

One common definition of a small baby at birth is one weighing less than 2 800 grams (or 6lb 3oz) at 40 weeks gestation. The average, normal weight for a baby born at 40 weeks is considered to be about 3 300 grams (7lb 5oz). This will vary though, and will often depend on the ethnicity of the parents (for example, babies of Asian parents are on average a little smaller). Babies born before 40 weeks would be expected to be less than this weight. Another method used to assess the 'normal weight' is 'percentiles' (or comparing the baby's weight with a scale of average birth weights).



A small baby may be said to be 'less than the 10th percentile' for its gestation (or in the lowest 10% of birth weights for a baby of that age at birth). This means the fetus weighs less than 90 percent of all other fetuses of the same gestational age. A fetus with IUGR may also be born at term (after 37 weeks of pregnancy) or prematurely (before 37 weeks).

Newborn babies with IUGR often appear thin, pale, and have loose, dry skin. The umbilical cord is often thin and dull-looking rather than shiny and fat. Babies with IUGR sometimes have a wide-eyed look. Some babies do not have this malnourished appearance but are small all over.



a journey of a prevature baby



Moment by Moment was born from experience and was passionately founded by the family of a 27weeker.

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Austprem Inc. is so very pleased to announce a further fundraiser with **Moment by Moment**. Moment by Moment is an online store which stocks many items including premature baby clothing and accessories. Austprem Inc. will receive 5% of any order you make! Just order the products you wish to purchase and add AUSTPREM at the check-out: www.momentbymoment.com.au



What Causes Intrauterine Growth Restriction?

Intrauterine growth restriction (IUGR) can begin at any time in pregnancy and it has various causes. IUGR results when a problem or abnormality prevents cells and tissues from growing or causes cells to decrease in size. This may occur when the fetus does not receive the necessary nutrients and oxygen needed for growth and development of organs and tissues. Early-onset IUGR is often due to chromosomal abnormalities, maternal disease, or severe problems with the placenta. Late-onset growth restriction (after 32 weeks) is usually related to other problems. Some factors that may contribute to IUGR include the following:

- **Maternal factors:** high blood pressure, chronic kidney disease, advanced diabetes, heart or respiratory disease, malnutrition, anemia, infection, substance abuse (alcohol, drugs), cigarette smoking
- **Factors involving the uterus and placenta:** decreased blood flow in the uterus and placenta, placental abruption (placenta detaches from the uterus), placenta previa (placenta attaches low in the uterus), infection in the tissues around the fetus
- **Factors related to the developing baby (fetus):** multiple gestation (twins, triplets), infection, birth defects, chromosomal abnormality

Why is IUGR a concern?

With IUGR, the growth of the baby's overall body and organs is limited, and tissue and organ cells may not grow as large or as numerous. When there is not enough blood flow through the placenta, the fetus may only receive low amounts of oxygen. This can cause the fetal heart rate to decrease placing the baby at great risk. Babies with IUGR may have problems at birth including:

- decreased oxygen levels
- low Apgar scores (an assessment that helps identify babies with difficulty adapting after delivery)
- meconium aspiration (inhalation of the first stools passed in utero), which can lead to difficulty breathing
- hypoglycemia (low blood sugar)
- difficulty maintaining normal body temperature
- polycythemia (too many red blood cells)

Severe IUGR may result in stillbirth. It may also lead to long-term growth problems in babies and children.



Austprem Inc. is a non-profit organisation with no on-going funding.

If you would like to make a donation to Austprem Inc., please send your cheque or money order to:

Austprem Inc. P.O. Box 2157 Sunbury VIC 3429

Please include you name and address so that a receipt can be posted to you. Donations \$2 and over are tax deductible.

How is IUGR diagnosed?

During pregnancy, fetal size can be estimated in different ways. The height of the fundus (the top of a mother's uterus) can be measured from the pubic bone. This measurement in centimeters usually corresponds with the number of weeks of pregnancy after the 20th week. If the measurement is low for the number of weeks, the baby may be smaller than expected. Other diagnostic procedures may include the following: Ultrasound, Doppler flow and Mother's weight gain.



How is IUGR managed?

Management of IUGR depends on the severity of growth restriction, and how early the problem began in the pregnancy. Generally, the earlier and more severe the growth restriction, the greater the risks to the fetus. Careful monitoring of a fetus with IUGR and ongoing testing may be needed. Some of the ways to watch for potential problems include the following:

- Fetal movement counting keeping track of fetal kicks and movements. A change in the number or frequency may mean the fetus is under stress.
- **Non-stress testing** a test that watches the fetal heart rate for increases with fetal movements, a sign of fetal well-being.
- **Biophysical profile** a test that combines the non-stress test with an ultrasound to evaluate fetal well-being.
- Ultrasound used to follow fetal growth.
- Doppler flow studies a type of ultrasound which use sound waves to measure blood flow.

Can IUGR be treated?

Although it is not possible to reverse IUGR, some treatments may help slow or minimise the effects. Specific treatments for IUGR will be determined by your physician based on: your pregnancy, overall health, and medical history, the extent of the disease, your tolerance for specific medications, procedures, or therapies, expectations for the course of the disease, your opinion or preference. Treatments may include:

- **<u>Nutrition</u>**: some studies have shown that increasing maternal nutrition may increase gestational weight gain and fetal growth.
- Bed-rest: in the hospital or at home may help improve circulation to the fetus.
- <u>**Delivery:**</u> when IUGR endangers the health of the fetus, then an early delivery may be necessary.

See references page 5

What is Austprem Inc.?

Austprem is registered as a non-profit organisation with the Australian Taxation Office. We are also an approved charity. Our aim is to provide support to as many of those parents of premature babies as we can. Your support can help us to achieve this goal.

Membership of Austprem is open to anyone who has a prematurely born baby or child. Further information about Austprem can be found at www.austprem.org.au, or by emailing austprem@austprem.org.au

Austprem also offers online support forums including *Austprem, Austprem - Pregnancy Support Group and Prematurity in the Press.*

Alicia Kerr

Better Out Than In! The Story of Byron

Byron was born in January 2005 at 32.6 weeks weighing 1020 grams, or 2lb 3oz. He was born by emergency caesarian suffering from severe IUGR. I had gone in for my 32 week check up, delayed by the Christmas break. I felt everything was fine overall but there just seemed to be a change in the way Byron was moving. I could still count more than 10 movements a day but it just wasn't the same as earlier on. The first indication of a problem was that my fundal height measurement was the same as my last check-up 5 weeks earlier. After some tests, I had to come back the next day for scans and was told I'd be admitted

then and there and they'd watch me for the next few days. Not long after they said he might have to come out that afternoon, and then revised that 20 minutes later to *coming out right now*. His heart-rate was dropping, he was presented franklin breech (bottom first), had both arms up around his head and had the umbilical cord wrapped around his neck. We were told he would do better out than in, and went straight into surgery.

Byron was lucky his lungs were formed when he was born and didn't need oxygen at all and apart from the usual issues of jaundice and weight gain, he was a very healthy baby. He was, as the doctors had suggested, better out than in. He was allowed to come home after 7 weeks in NICU and SCN with steady weight gains and was 2kg by his due date. The only ongoing issue is weight gain - Byron has never moved from the 3rd percentile in weight but he's healthy and growing in proportion which are the two most important things.

In terms of why, we just don't know. The placenta was taken away for testing with no reason found for the IUGR. I don't smoke or drink, was very careful with food and hadn't been sick at all during my pregnancy. The only unusual event was having a bit of dentistry work done, including a root canal. I was told there was no evidence to link the two events, but it was a possibility. I don't know if it would happen in subsequent pregnancies but can easily say I'm just very happy to have one beautiful happy healthy boy and couldn't ask for more. Byron turned two in January this year and is full of beans and full of joy!!



References and Further Reading

http://www.healthsystem.virginia.edu/uvahealth/peds_hrpregnant/iugr.cfm_University of Western Virginia

This site offers a wealth of information on health in general. The IUGR section was particularly helpful as a reference for this article.

http://familydoctor.org/313.xml familydoctor.org

This site answers your questions about anything and everything. This link focuses on Intrauterine Growth Restriction. It also offers print-friendly versions of articles.

http://www.aafp.org/afp/980800ap/peleg.html http://www.rwh.org.au/nets/handbook/index.cfm?doc_id=821 http://chorus.rad.mcw.edu/doc/00942.html http://www.patient.co.uk/showdoc/40000204/ http://www.magicfoundation.org/www/docs/113/small_for_gestational_age.html http://www.magicfoundation.org/www/docs/985.803/

Joining Austprem

Austprem is an Internet based support group.

To join Austprem Inc., you will need to go to <u>http://www.austprem.org.au/join.html</u> and fill out the online membership form. To access the online forums and chats (where most of the Austprem "action" happens), you will also need to follow the steps at

http://www.austprem.org.au/ forums.html to register with mc2 and subscribe to an Austprem group.

Join now - it is a great opportunity to share with others who have "been there" and who can understand your experiences.

Membership is FREE!

Any information provided to Austprem is held in confidence and will not be used for any other purpose or given out to any third party without your permission.



PremiePress

PremiePress is a publication for those who are interested in the development of premature infants and prematurely born children.

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Austprem Forums / Message Boards

Austprem - Forum

Austprem provides a forum for Australian and N.Z. parents and caregivers of premature (or preterm) babies to discuss the issues and experience of prematurity in a local context. We welcome parents, extended family, NICU and MCH nurses and any interested health professionals. Through Austprem, families who have experienced the complex challenges of parenting a premature baby, reach out to other families facing this journey and offer friendship, information and support. Medical professionals are encouraged to participate in the discussions both to learn about the parental experience of prematurity and to offer insight and understanding.

→<u>Austprem - Pregnancy Support Group</u>

The Austprem – Pregnancy Support Group has been set up for those who are contemplating or experiencing a pregnancy following a preterm birth, and for those at risk of giving birth prematurely.

Everyone is welcome to join Austprem – Pregnancy Support Group. You might be pregnant again, you might just be thinking about another pregnancy or you might have already completed a subsequent pregnancy and want to support someone else who is just starting on the journey. Sharing your thoughts and experiences might just help another mother, and support is what Austprem is all about.

Prematurity in the Press

This Austprem group is an online forum where summaries/abstracts of articles in journals, print/online media and book reviews etc that feature issues about prematurity are posted. Where possible links to the full text of the article will also be included, but this depends on the availability of the article and Copyright. This group is a semi-public group, nonmembers are able to read forum, but only members can post articles to the group and join in any subsequent discussions.

Take a look at http://www.austprem.org.au/forums.html for information on how to join any of these Austprem Forums

The Story of Xander







Xander was born on the 19th of February 2004 due to my developing pre-eclampsia. He was born by c-section at 27 weeks gestation weighing 535g and measuring 29.5cm long. He was ventilated at birth and just 4 days later graduated to CPAP and remained on CPAP until the start of May. While Xander came off the ventilator with no issues, it was a long drawn out process to wean him off the CPAP.

When he was born, we were very lucky, because he did not lose much weight. He lost 10g the first day and from then he either stayed at the same weight or gained weight. But it seemed to be a very slow process. Xander tried a couple of times before his gut was able to handle milk and from then on he seemed to progress in leaps and bounds.

The fun began when trying to establish breast feeding. It took a while before the lactation consultant suggested using a nipple shield which worked wonders. After that the hardest part was trying to prevent him from being a sticky beak like his Mum during meal times! We managed against the odds to bring Xander home and breastfeed him until he was 10 months old (actual).

Xander's growth was pretty steady but never great. He is still a very small boy for his age. When we got to bring him home after 15 weeks he weighed 2.37kg. At 6 months he weighed 3.26kg and at the age of 1 he weighed 6kg. He is now 3 and still only weighs about 10kg, although he has just had a growth spurt so hopefully he now weighs a couple of kilos more.

Xander is a slight boy with not much body fat on him and when he gets sick it is sometimes a worry, because he doesn't have the reserves of other kids his age and seems to take longer to recover. None of his doctors have ever mentioned that there's anything to worry about with his weight, as his weight gain, although not anywhere near the percentiles, follows the curve. The other side to this is that Xander appears to be quite muscly and will hopefully have well defined muscles like his uncle when he gets older!

We've been lucky because we had a fairly straight forward journey through the nursery and most milestones were reached at appropriate times. There were some worries about Xander's speech, but he picked that up just before we saw the speech pathologist. We have been referred to an occupational therapist, some of this is due to Xander being our first baby, others things are because he has difficulty concentrating. We are slowly working through this and are on a waiting list for group therapy.

Xander is now a happy 3 year old who has very little fear about almost anything and will still try things while scared. He runs with and often outdoes his 4 year old cousins. We are proud of him and what he has achieved so far in life.

Xander was born by c-section at 27 weeks gestation weighing 535g!

Robyn Turnor

Having An IUGR Baby - The Story of Hunter Rachael Mackay

I was an intrauterine growth restricted baby and my little boy, Hunter (2/3/07), is too. I was born at 37 weeks and I weighed only 2 pounds and 12 ounces and measured 40cm in length. Hunter was born at 35 weeks and weighed just 1705 grams and measured 44cm in length. We are not sure if Hunter's IUGR was caused bv pre-eclampsia or by Russell-Silver Syndrome, which is what caused mine. We are currently waiting for test results to come back that may confirm RSS.

What is it you ask? Russell-Silver Syndrome is a very rare genetic disorder characterised by growth delays before birth (prenatal or intrauterine

growth restriction). It is one of five types of primordial dwarfism. Genetic problems are thought to cause this syndrome, although the specific gene/s remain to be discovered. The pattern of inheritance has not been determined, but in most cases it seems to occur without any family history of the condition. Children with Russell-Silver Syndrome are born small and generally achieve less than 5 feet at adult height.



Hunter at 6 days.

We are not sure if Hunter's IUGR was caused by pre-eclampsia or by **Russell-Silver** Syndrome...



Hunter now (12.4.07)

Hunter is Now 13 months old and weighs 7.5kg, He stands at 71cm and his head is 45.6cm. He is seeing a paediatrician at Epping regularly. She is doing tests on Hunter at the moment to see if he has RSS. But at this stage we're unsure. She thinks he does have RSS and his bone age is that of a 3-6 month old. But other than that he is going well. He is crawling and almost walking, talking, and getting some teeth. He is growing okay and slowly getting there and other than his growth the paediatrician is really happy with him. I have included a link to a website for anyone interested in more information on Russell-Silver Syndrome:

http://www.magicfoundation.org/www/docs/112/russel_silver_syndrome.html



A number of Austprem members have submitted their children's weight and length data at various ages so that we can all gain some perspective on how prem babies grow.

You can see the resulting chart at http://www.austprem.org.au/journey/home/growth.shtml

Further contributions most welcome!

Obvious IUGR—The Story of Jordan Martha Morley-Buchanan

My Jordan was born at 30wks weighing 497gms with obvious IUGR. There was no real sign of any major problems other than the fact that I wasn't putting on weight and he didn't move a lot. Being my first baby I didn't know what to expect but I was becoming more concerned as the weeks progressed.

At my 28 week appointment I voiced my concerns and the Gynecologist, very old school doctor, told me that "these babies are very lazy and they sleep a lot and move when you don't realise it." It took him ages to get the heart beat and when I asked if that was possibly because the baby was not developing properly, he told me he just needed new batteries for his Doppler.

I finally, on 19th April 1994, phoned the obstetrician who had done my previous scans and told him that I needed some peace of mind. No, I didn't have a referral but it had been weeks since I felt my baby move.... Needless to say I got an appointment within a few hours and I picked Kent, DH, up on the way.

The scan showed that the baby had virtually no fluid around it and that no nutrients were entering the placenta. Baby had stopped moving to preserve brain and heart function - we needed to get this baby out.

Two hours later I was having a C-section under general anaesthetic and a classic caesar to boot.

When Jordan Bray Morley-Buchanan was born I was still under and Kent had to watch the horrifying 20 minutes it took to revive and pink him up. He said that for a few minutes he was looking between me out cold, looking dead and Jordan - grey and lifeless looking and he felt his whole world sinking through the floor.

Anyway, Our precious boy survived, but it took 19 weeks before we took him home and at that stage he was only 2500gms. We really struggled with feeding him as he was very refluxy and would only tolerate small feeds, thus his weight gains were very small.

Right up to the age of 6 he was still tiny, generally wearing size 2 clothes, then all of a sudden he stopped getting sick all the time, no more infections, viruses etc. and he started putting on weight. For the past few years we had started worrying about him putting on too much weight, but he has just turned 13 and he has really slimmed down.

It seems so superficial to condense 13 years into such a small piece of writing, but we do survive after plodding one day at a time and listening to as much advice as there is available and then choosing what seems right for you and your baby.

Right up to the age of 6 he was still tiny, generally wearing size 2 clothes, then all of a sudden he stopped getting sick all the time...





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25 Benjamin (6) 25 Samuel (2)

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22 Arielle (1)

23 Brice (12)

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26 Dwayne (1) 26 Leisel (1) 27 Aaron (1) 28 Brett (4) 28 Sally (3) 29 Gabrielle (12) 29 Lucas (2)

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27 Harper (2) 28 Max (1) 29 Memphis (10) 29 Lachlan (8) 29 Samantha (2) 29 Caleb (1) 30 Brae (10) 30 Joel (10) 30 Abigail (6) 30 Bella (5) 30 Jack (5) 30 Kye (2) 31 Zoe (7) 31 Aleesha (3)

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Our Angel Jesse born 9th July 2004



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Celebrating Birthdays

If you would like your children (full term and prem) listed in the Austprem Ink newsletter, or to be added to the Birthdays page at http://www.austprem.org.au/journey/ superheroes/birthdays.shtml please email kirsten@austprem.org.au





Order your toys online, get great products, delivery to your door and support Austprem too!

Simply nominate Austprem, Sunbury, VIC as the fundraising recipient at Step 5 when you order.

http://www.toysandmore.com.au







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Fundraiser

Purchase address labels, stick on and iron on name labels for clothing, bottles, snack boxes etc, and heaps of other stuff, and support Austprem too!

Order at

http://www.younameitlabels.com using our code <u>aiv0603</u> (all lower case, no spaces). More details from: http://www.austprem.org.au/promotion/ you_name_it.shtml

Want to Chat?

Chats are a great way to get to know other members better. They are usually held on Thursday (not in January) and Sunday nights. A reminder is usually posted to the Austprem Forum the day before a chat, so check there for the exact time. The chats are held in the Austprem Chat Room on the mc2 site, so only Austprem members are able to attend.

Chats are very informal - you can turn up in your pyjamas and you don't need a babysitter. But you can still receive great support and understanding from other parents, or just have a social chat - a bonus if you have been isolated at home all day.

Chats times (for Thursday and Sunday nights):

7:00pm	WA
8:30pm	NT, SA
9:00pm	VIC, TAS, ACT, NSW, QLD
11:00pm	NZ

These times may change, so please check the Forum for reminders and updates.



Copies of Austprem Ink

may be downloaded from:

http://www.austprem.org.au/newsletters.shtml





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Disclaimer

Please note that Austprem Inc. does not recommend that any interventions are made to any baby or child without the knowledge and assent of the child's doctor or other health care provider.

Austprem Inc. cannot be held liable for the actions of any person based on information that Austprem Inc. has provided. Please check with your doctor or health care provider as to what interventions are appropriate for YOUR baby!

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Austprem Ink Puzzle Corn	ev Rebecca Lavender-Roberts
 On a newborn baby with IUGR, this is often thin and dull-looking rather than shiny and fat (two words 9,4). Sometimes to father cuts it. 	 It can be hard to find these to fit an IUGR baby. An IUGR baby may score low on this test at birth.

- 3. This is a more accurate way of measuring fetal size.
- Often the cause of IUGR is this. 7.
- 9. Intrauterine Growth Restriction.
- 13. IUGR babies are _____ all over.
- 15. When a baby is born early.
- 16. A fetus with IUGR often has an estimated fetal weight less than this percentile.
- 17. A doctor may suspect IUGR when they measure this.

- An IUGR baby may score low on this test at birth. 4.
- 5. An IUGR baby may spend a lot of time here.
- 6. This special cot helps small babies who can't maintain their body temperature.
- 8. Small gains of this during pregnancy may correspond with a small baby.
- 10. The period of development in the uterus from conception until birth.
- 11. Problems with this can cause IUGR.
- 12. Some times this can help improve blood flow to the fetus, in hospital or at home.
- 14. Unborn young from the end of the eighth week after conception to the moment of birth.



Your Austprem

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Austprem Ink

Premature birth, babies and beyond



Website:

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Benefits to all involved

Ritchies Community Benefit Card

Buy your groceries, and support Austprem too! Simply nominate Austprem Inc. as your CB Card recipient and 1% of your purchase total will be donated to Austprem. The Ritchies Community Benefits Program operates in both Victoria and NSW. Victoria: Austprem Inc. CB number is 93772 NSW: Austprem Inc. CB number is 93807 More information:

http://www.austprem.org.au/promotion/ritchies.shtml

Crossword answers—from page 13.



Austprem Inc. Premature birth, babies and beyond

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