Small-for-Gestational-Age (SGA)

Introduction

Between 3% and 10% of live births each year are described as "small-for-gestational- age" (SGA). In addition, older children who are of short stature and underweight may be labeled SGA by their physicians. There are many variances in the definition of SGA, but generally, SGA describes a child whose birth weight and/or length is/was less than the 3rd percentile (with age adjusted for prematurity). In addition, when ultrasound evidence demonstrated poor fetal growth while in-utero, an infant is also described as being "IUGR" (intrauterine growth retardation). These definitions are descriptive terms and are not specific diagnoses.

The factors behind why an infant is born SGA can be quite complex. The factors include fetal (such as genetic syndromes), maternal (such as substance use or infection), placental, and/or demographic (mother's age, income level, race).

But setting aside these possible reasons, the fact is that 9 out of 10 infants born SGA do experience catch-up growth by the age of 2 years, and usually by 6 months of age! It is the smaller subset of SGA children, the 1 of 10 who fail to achieve catch-up growth by age 2, that we will focus on in this brochure- - - the short SGA child.

These include "idiopathic" SGA children -- children who are small for unknown reasons - - parents who are of normal height, history of non-smoking/non-drinking, lab tests have ruled out known causative factors, etc. It can be frustrating to be the parent of a short SGA child, you want answers to why your child isn't growing. In this brochure, we hope to offer information on SGA children, and to answer some of the possible questions you may have regarding SGA.

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What Does "SGA" Mean?

SGA (small-for-gestational-age) generally describes any infant whose birth weight and/or length was less than the 3rd percentile (adjusted for prematurity). "IUGR" is a term also commonly used, and describes the small infant who had poor fetal length growth demonstrated while in-utero by ultrasonography. "SGA" is currently used to describe any child born smaller than average in both length and weight. In this brochure, we will be focusing on the SGA child whose length and possibly weight has not caught up to what is appropriate for their age, and for whom doctors can not determine any reason for the child's smallness.

How is SGA Diagnosed?

Pediatricians usually begin by looking at all the possible factors for a child being born too small - maternal, environmental, and others. A pediatrician may send an SGA child to a geneticist, to see if the child's features fit any number of short-stature syndromes (some determined with lab tests, others by examination). An endocrinologist may run other tests, again ruling out all possible endocrine and metabolic reasons behind the child's poor growth.

Recall that between 3% and 10% of live births are small-for-gestational-age -- we are focusing on the small subset of these births where the children's growth stays on their lower growth curves and does not "catch-up" to any higher percentile. Sometimes an unknowing doctor may say "well, your child is OK because he is still following his own growth curve." Never mind that the boy's growth curve is below the 3rd percentile!

What are Typical SGA Characteristics?

Clearly, the typical SGA child is shorter and thinner than his or her peers. But the range of other characteristics can vary. A list of common characteristics and more information on SGA is listed below:

Characteristics Seen in Almost all Short SGA Children:

- low birth weight; probably low birth length
- inadequate catch-up growth in first 2 years
- persistently low weight-for-height proportion
- lack of muscle mass and/or poor muscle tone

Open to Insert

Major Aspects of Growth In Children

The MAGIC Foundation is a national non-profit organization created to provide support services for the families of children afflicted with a wide variety of chronic and/or critical disorders, syndromes and diseases that affect a child's growth. Some of the diagnoses are quite common while others are very rare.

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Continues and develops through membership fees, corporate sponsorship, private donations and fundraising.

Small-for-Gestational Age "SGA"

The MAGIC Foundation

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Other Common Characteristics of Short SGA Children:

- lack of interest in eating
- fasting hypoglycemia & mild metabolic acidosis
- generalized intestinal movement abnormalities:
  a) esophageal reflux (may be silent with no spitting up)
  b) delayed stomach emptying
  c) constipation
- blue sclera (bluish tinge in white of eye)
- late closure of the anterior fontanel (soft spot on the skull)
- frequent ear infections or chronic fluid in ears
- congenital absence of the second premolars
- delay of gross and fine motor development
- delay of speech and oral motor development
- delayed bone age early, later fast advancement
- early pubic hair and underarm odor (adrenarche)
- early puberty or rarely true precocious puberty
- classical or neurosecretory growth hormone deficiency
- possible attention deficit disorder (ADD) or specific learning disabilities
- possible kidney abnormalities

What Should I Do If My Child is Diagnosed SGA?

- Make sure your child is measured carefully & frequently. KEEP YOUR OWN RECORDS. Find an endocrinologist who knows how to treat SGA children's growth failure and discuss the options.
- Find a pediatrician who is willing to learn from experts about SGA children, and will coordinate care and opinions with consulting specialists.
- Have your child evaluated by a pediatric gastroenterologist if your child struggles to gain weight. She/he may consider a test for slow gastric emptying and reflux (the latter preferably with a pH probe test).
- Get adequate calories into your child. Insufficient nutrition & low blood sugar damage the developing brain and compound the growth failure.
- Take necessary measures to prevent hypoglycemia in young SGA children. Pay special attention to the night when everyone is asleep, anytime your child is ill or not eating normally, and when your child is unusually active or stressed.
- Know clues that hypoglycemia (or the spilling of ketones) may be occurring:
  a) waking to feed at night past early infancy
  b) excessive sweating
  c) extreme crankiness improved by feeding
  d) difficulty waking up in the morning
  e) ketones in the urine
- Prevent hypoglycemia (primarily in the underweight SGA child) by:
  a) feeding frequently during the day & night
  b) keeping snacks with you at all time
  c) adding glucose polymer in infant's, & cornstarch in child's, bed- & night-time feeding
  d) keeping glucose gel with you at all times
  e) making prior arrangements with your doctor and local ER to start IV glucose if feeding is impossible
  f) having urine ketone sticks at home (over the counter)
- Monitor skeletal maturity (bone age x-ray) annually
- Treat your child according to his age not his size. Arrange safe, age-appropriate activities; buy age-appropriate clothes; and expect age-appropriate behavior and responsibility.
- Watch your child's psychosocial and motor development. All states have developmental evaluation & intervention services for children less than 3. These programs are based on the child's needs not parental income. For children over 3 years, the school district becomes responsible for providing these services. Take advantage of this; intervention can make a world of difference for your child!
- Seek appropriate consultation for recurrent ear infections, or any other medical issues. But remember:
  a) Only emergency surgery should be done until the child is gaining weight well.
  b) A young underweight SGA child should NEVER be fasted or kept NPO for more than 4 hours for ANY reason without glucose-running IV.
  c) For surgery, IV glucose should be given during the procedure and continued in the recovery room until the child can eat again.

What Can I Expect Regarding My Child's Cognitive Abilities?

An infant with SGA is generally born with normal intelligence. Learning disabilities and ADD may be increased in incidence in SGA. Autism and similar disorders like pervasive developmental disorder (PDD) may also be increased. It is unclear whether these problems just appear to be increased in SGA, are innate to SGA, or are related to SGA through early malnutrition and hypoglycemia, both of which are preventable.

Does a Delayed Bone Age Mean My Child Will Have Catch-Up Growth Later?

Although most if not all SGA children have a bone age that is relatively delayed compared to their chronological age, studies have shown bone age to be an unreliable predictor of adult height in SGA children. One possible reason is that many SGA children experience a rapid acceleration of their bone age just prior to the onset of, and during, puberty. Within a span of just 12-18 months, an SGA child's previously delayed bone age can quickly surpass his chronological age, negating any "extra growing time" that usually is present with delayed bone age.

It is therefore important to monitor an SGA child's bone age, to ensure that it does not begin to advance. For the older SGA child, bone ages are also used to determine if any incremental height remains for the child (as long as the bone plates are open and not fused).

How Can I Help my SGA Child Grow?

Simplistically, there are two aspects of the SGA child's growth -- weight and height. Particular attention should be paid to weight gain during the first 2 to 3 years of life, as many children born SGA may struggle to gain weight (although ironically, some children born SGA may gain excessive weight during childhood). As previously discussed, a pediatric GI doctor can help diagnose and treat, or rule out, any GI medical issues that may impede an SGA child's ability to gain weight. Reflux (often silent) and delayed gastric emptying appear to be the most common of these GI problems. A nutritionist can also help provide advice on simple additives and other means of adding calories to a child's diet. There are also medications like the antihistamine "cyproheptadine" (brand name: Periactin) which can act to increase an SGA child's appetite. Please contact MAGIC for more in-depth literature on this topic.

The second growth aspect is length/height. More than 90% of children born SGA catch-up to normal height by 2 to 3 years of age. Among those who do not, inadequate caloric intake may contribute to growth failure. If optimum caloric intake can be attained, some "catch-up" in weight and height growth curves may occur. If a child is still significantly short after this period, and the child is 2 to 3 years old or older, then the family may consider growth hormone therapy in order to increase the child's height growth velocity.

It is important to note two things. First, research has not found any means except growth hormone therapy to stimulate catch-up growth, maintain a normal height during childhood, and increase an SGA child's adult height. The United States F.D.A. approved growth hormone therapy as "…long-term treatment of children who were born SGA and who have not achieved catch-up growth by the age of 2." Second, most SGA children are not GH deficient according to standard testing measurements. Studies are ongoing, but it appears that many of these short SGA children do not respond normally to growth hormone and thus require more growth hormone than the typical child. Instead of being growth hormone “deficient”, experts now consider SGA children to be growth hormone “insufficient.”

Deciding About Growth Hormone Therapy

The decision to begin growth hormone therapy for an SGA child can be an easy decision for some parents, and a difficult one for others. Not all parents choose this treatment for their child. We at MAGIC will support you in whatever choice you make. However, remember that growth hormone therapy is the only treatment currently available to increase the SGA child's height.

Your doctor will help you in this decision process, and many factors must be considered. Factors discussed may include potential incremental height for your child (based on the parents' height), whether your child can benefit from the possible added muscle mass and strength, your child's age, bone age, other health issues of your child, and insurance coverage or the possible pharmaceutical company assistance. Growth hormone therapy requires a commitment. However, the initial commitment can be for a trial period of at least 6 months to determine growth response. The injection is a simple subcutaneous (top layers of skin) injection every night. Most children and parents who have chosen this treatment think it has turned out far better and far easier than they expected. If you are interested in talking with other families who have chosen or declined growth hormone therapy, MAGIC can connect you.

Are There any Other Health Issues Associated with Being Born SGA?

Multiple studies, short-term and longitudinal, have found an increased risk of health problems such as insulin resistance, cardiovascular disease, hypertension, obesity, and type 2 diabetes among adults who were born SGA or with low-birth weight. Explanations for these risks vary from intrauterine nutrition to genetic causes. In addition, some correlations have been found between persistent short stature and psychosocial difficulties and/or behavioral problems. Clearly, a great deal of research still needs to be done to narrow down and clarify the exact risks of being born SGA and identify which children are at risk. Until then, children and adults born SGA should be monitored carefully by their physicians in light of these possible risks.

Coping

Coping with the time-consuming special attention and services necessary to care for an SGA child can be overwhelming, especially if you try to face it alone. Good physicians may have no experience with routine needs of SGA children. Day-to-day challenges such as feeding, formulas, fitting clothes, school issues and peer pressures can be less stressful if you are in contact with other families who "have been there". Making connections between families with similar issues and facilitating sharing of information and experience is a major goal of the MAGIC Foundation’s RSS/SGA Division. We can put you in touch with other people who have had, and have solved, problems similar to yours.

The treatment of SGA children's problems should be approached in a systematic and timely fashion. The major problems that require intervention in the various age periods are all different, but most all these problems can be solved or dealt with successfully if you get the help you need. It is beyond the scope of this brochure to go into specifics on various treatment protocols. Feel free to contact MAGIC for more in-depth information.

Most importantly, be your child's #1 advocate, trust your parental gut instinct, and love your beautiful SGA child. We at MAGIC will be here to help you in whatever way you need.