

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 (gestational age). Between 3% and 10% of live births each year are diagnosed as SGA. In addition, when ultrasound evidence demonstrated poor fetal growth while in utero, an infant may also be described as "IUGR", which means that the fetus experienced intrauterine growth restriction.

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 – these are both rare).

But setting aside these possible causes, 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. Catch-up growth typically means that the child's length curve moves upward, crossing the 3rd percentile line at a minimum and ideally getting closer to the percentile curve the child should be at based on his or her parents. It is the smaller group of SGA children, the 1 of 10 who fail to achieve catch-up growth by age 2, that are often referred to as "short SGA" and who are our focus.

This group of short SGA children typically include "idiopathic" SGA children – children who remain small for unknown reasons...parents who are of normal height, there is a history of non-smoking/non-drinking, and lab tests have ruled out known causative factors. It can be frustrating to be the parent of such an SGA child – you want answers to why your child isn't growing. Here we hope to offer information on SGA children and to answer some of the possible questions you may have.

How is it Determined if my Child was Born SGA?

An SGA diagnosis is given when a newborn's birth weight and/or length is -2SDS (standard deviation scores) below the mean (0.05SDS/50th percentile) for the child's gestational age [-2SDS equates to approximately the 3rd percentile]. The gestational age of the newborn is the essential factor -- a newborn who weighs five pounds at birth would be SGA if born at 38 weeks gestational age but would not be SGA if born at 37 weeks gestational age. A physician will use a set of published standards to determine a newborn's birth standard deviation scores. This determination can be made at birth or anytime in the child's future, as long as the gestational age is known along with the birth weight and/or length. The MAGIC Foundation can also let you know if your child was born SGA – simply email sga@magicfoundation.org with your child's gestational age (how many weeks and days pregnant the mother was when the child was born), the birth weight and birth length.

What Assessments Are Typically Performed in Evaluating a Child Born SGA?

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 by lab tests, others by examination). If the SGA child has not shown evidence of catch-up growth by age 12-24 months, the pediatrician should refer the child to a pediatric endocrinologist (a physician who specializes in growth) for evaluation. An endocrinologist may run additional tests, again ruling out all possible endocrine and metabolic reasons behind the child's poor growth. And keep in mind that if a child has parents whose adult height is at the 3rd or 5th percentile, the child may be what is termed "constitutionally SGA" – meaning the child is small because the parents are small.

Sometimes a physician may tell a parent that the child is "growing at a normal rate" or "following his own curve." And indeed this may be correct – the child's length curve may be perfectly paralleling the 3rd percentile, just below it. This is quite common. But the child should be catching up! If your child's height remains below the 3rd percentile by 2 years of age (or in cases of taller parents, remains very far below the height percentile he should be at for his family), the child needs to be seen by a pediatric endocrinologist.

Are There Certain Physical Characteristics That Are More Common in Children Born SGA Who Fail to Catch-Up in Length/Height?

The typical short SGA child is clearly thinner and shorter than his or her peers, but the range of other characteristics can vary. A list of possible characteristics 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

Other Common Characteristics of Short SGA Children:

- lack of interest in eating
- fasting hypoglycemia & mild metabolic acidosis
- generalized intestinal movement abnormalities:
 - a. esophageal reflux resulting in movement of food up from stomach into food tube (esophagus)
 - b. delayed stomach emptying resulting in vomiting or frequent spitting up
 - c. slow movement of the small intestine &/or large intestine (constipation)

- late closure of the anterior fontanel (soft spot on the skull)
- delayed bone maturity (bone age) early, later fast advancement
- 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
- early pubic hair and underarm odor (adrenarche) [associated with sudden bone age advancement]
- early puberty or rarely true precocious puberty
- classical or neurosecretory growth hormone deficiency
- ADD/ADHD and/or specific learning disabilities
- blue sclera (bluish tinge in white of eye)
- hypospadias (abnormal opening of the penis)
- cryptorchidism (undescended testicles)
- possible kidney abnormalities

What Should I Do If My Child is Diagnosed SGA?

- Have your child's diagnosis confirmed by a doctor who is familiar with SGA patients or is willing to learn. Consider becoming a member of The MAGIC Foundation and in addition, you will then receive a free copy of the 330-page guidebook titled [RSS/SGA – A Comprehensive Guide: Understanding Aspects of Children Diagnosed with Russell-Silver Syndrome or Born Small-for-Gestational-Age](#).
- Make sure your child is measured carefully & frequently – every 3-4 months is ideal. This may mean going into the pediatrician's office just for a weight/measurements check. Your child's length/height should be measured THREE times and the average of the three measurements is the one that is recorded. 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 the unique health issues of short SGA children, and who will coordinate care and opinions with consulting specialists.
- Get adequate calories into your child. Insufficient nutrition & low blood sugar levels damage the developing brain and compound the growth failure. However, due to the increased risk for insulin resistance and related health issues, it is important that an SGA child also remain as lean as possible (often with a BMI between 13-16, the lower end if the child has low muscle tone and the higher end if the child has good muscle tone).
- Hypoglycemia can be a significant risk for 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. Download the SGA emergency medical instruction document from the MAGIC website if your child is unable to eat for more than 4 hours and/or is spilling ketones in urine. We recommend that you download and read this document, and understand it, *before* you have a medical crisis.

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 (by mouth or gastrostomy tube)
- 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

- 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.
- Monitor the child's skeletal maturity with annual bone age x-rays. Once the bone age begins to advance or the child is in puberty, the x-rays should be repeated every 6 months.
- 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, hypospadias, undescended testicles, or any other medical issues. But remember:
 - a. Only emergency surgery should be done until the child is gaining weight well.
 - b. A young 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/ADHD 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 We Improve our Child's Weight?

Improving weight can involve one or more of the following treatment methods: nutritional changes (both ways to increase quantity of calories as well as changing types of food that digest faster to allow for more natural hunger); identification and resolution of reflux (often asymptomatic); identification and accommodations for delayed gastric emptying; and identification and resolution of constipation (often one of the biggest causes of suppressed appetite); the use of an appetite stimulant called cyproheptadine; and finally, the possibility of moving to gastrostomy tube feedings.

But it is imperative that the SGA child's physician be aware of the recommendations for keeping the SGA child as lean as possible (typically with a BMI between 13-16 depending on the child's muscle mass) due to the increased risks for health issues associated with metabolic syndrome. Research has found that these risks increase with rapid weight gain catch-up, or even with small amounts of extra subcutaneous body fat, for an SGA child.

On the other hand, short SGA children cannot grow on air – meaning their length/height can be diminished if they do not

consume enough calories. It is a balancing act and not an easy one. Please connect with the MAGIC Foundation's SGA division consultant if you have any questions.

Can My Short SGA Child's Height Be Improved?

Yes, the height of a short SGA child can be improved above the 3rd percentile and closer to where he should be for his parents through the use of recombinant growth hormone therapy (rGHT). In 2001, the U.S. FDA approved the use of rGHT as long-term treatment of growth failure in children who were born small-for-gestational-age and do not achieve catch-up growth by age 2. And in 2003, the European Agency for the Evaluation of Medicinal Products (EMA) made the same approval for SGA children who had not achieved catch-up growth by age 3.

In addition, almost universally, research in the last two decades have found that growth hormone therapy increases childhood height for SGA children to a percentile in the "normal" range, and that rGHT also increases and normalizes final adult height. And possible more important, rGHT has been found to result in many other improvements in health for SGA children.

The choice of whether or not to increase the short SGA child's significantly shorter stature is a personal decision that must be made by each family, and balanced with the other health improvements that can come with using rGHT. Each child's parents and endocrinologist should discuss the benefits and risks of rGHT, and discuss the various factors that impact the success of rGHT, as they relate to their specific child.

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.

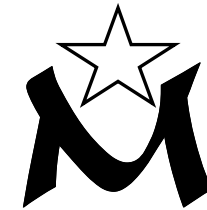
Written by:

Madeleine D. Harbison, M.D.
Assistant Professor of Pediatrics
Adrenal and Steroid Disorders
Pediatric Endocrinology
Mt. Sinai School of Medicine of NY University
New York, New York

This brochure is for informational purposes only. Neither The MAGIC Foundation nor the contributing physician assumes any liability for its content. Consult your physician for diagnosis and treatment.

Revised 2.2017

Small-for-Gestational-Age



The MAGIC Foundation®
For Children's Growth

“Children have a short time to grow and a lifetime to live with the results” ®

Not an illusion or magical,
But the caring for children
and their families

* * * *

Dedicated to the growth
and overall development
of children

4200 Cantera Dr.
Suite 106
Warrenville, IL 60555
630-836-8200
630-836-8181 fax
800-3MAGIC3
www.magicfoundation.org