



Child Growth Foundation

**A guide to growth conditions and how
we support those living with them**



About Us

The Child Growth Foundation (CGF) is a UK charity dedicated to supporting people living with rare growth conditions. We provide information and support to those directly affected, their parents and the healthcare professionals who will work with them.

We also raise awareness of growth conditions among the general public and health professionals and we fund research to increase medical understanding of these conditions.

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About Growth

Growth is the most sensitive index of health in childhood. You only grow when you're a child and the major influence on your final height is genetic, so you may be short or tall simply because your parents are.

Most children, around 95%, grow perfectly normally. For the

remaining 5% consistent, accurate and regular measuring and monitoring will help. There may be explanations for the irregular growth such as childhood illness.

In a rare number of children the reason may be due to an endocrine or genetic growth condition.

About Growth Conditions

There are a number of factors that can affect a child's growth. At the Child Growth Foundation, we support the families of children where the reason for the growth issues are due to congenital or hormonal problems. This means the child was born with a growth condition or there have been complications within the endocrine system that uses hormones to control growth.

Growth conditions can be grouped into two broad definitions, overgrowth and undergrowth. As the names suggest, an overgrowth condition is where the child is considerably

taller than average and an undergrowth condition is where the child is considerably shorter than average. The CGF supports many growth conditions and each present in different ways and come with a variety of other symptoms.

The conditions supported are all 'rare conditions', which often means that medical understanding is limited, and appropriate support is varied. Diagnosis for some conditions is not achieved for some time, leaving parents worried about what is happening to their child.



SGA/IUGR/SRS

Small for Gestational Age/Intrauterine Growth Restriction

Small for Gestational Age (SGA) is a term given to a baby that is born smaller than normal when compared to other babies that had the same number of weeks of pregnancy. Babies may be born SGA through genetics (both parents are small) but they may be small because of problems during pregnancy.

Intrauterine Growth Restriction (IUGR) is when a baby is born at full term but weighs below 2.5kg. This would indicate that growth within the womb has been unsatisfactory. IUGR commonly occurs when the foetus does not receive the necessary nutrients and oxygen needed for proper growth and development of organs and tissues.

Around 90% of babies born SGA/IUGR will catch up over the first few years of life. This can affect the diagnosis of other problems as medical professionals will work with the assumption that the baby will be one of those 90%. Careful observation and monitoring is needed to determine if the SGA/IUGR is an indication of other

conditions, such as SRS.

Silver-Russell Syndrome (SRS)

SRS is a rare undergrowth condition affecting around 1 in 20,000 to 1 in 50,000 births each year and is characterised by slow growth during pregnancy and after birth. Following birth, babies with SRS will fail to gain weight at the normal rate (failure to thrive).



Children with SRS may encounter a number of problems. However, not every child will experience all of these and the severity of each will be different. Along with the short



GHD/MPHD/SPIGFD

stature many children with SRS will have a small triangular face and prominent forehead. There may be body asymmetry, an increased risk of delayed development, speech and language problems and possible learning difficulties. There can also be digestive problems and children with SRS are likely to have reduced appetites and can develop ongoing issues with low blood sugar.

Growth Hormone Treatment (GHT) may be offered from the age of 4 years, under the SGA Nice Guidelines.

Growth Hormone Deficiency

Growth hormone deficiency is a condition caused by a shortage of growth hormone, sometimes even a complete absence of growth hormone. It affects between 1 in 3,000 and 1 in 10,000 people and the lack of growth hormone will restrict the child's growth resulting in a much lower than average height.

Multiple Pituitary Hormone Deficiency

Multiple Pituitary Hormone Deficiency is a condition caused by a shortage of several hormones produced by the pituitary gland. It

has similar characteristics of GHD but comes with additional complications by the absence of other hormones including thyroid-stimulating hormone and cortisol, the hormone associated with the body's fright and flight response.

MPHD is also known as Combined Pituitary Hormone Deficiency or hypopituitarism

Severe Primary IGF-1 Deficiency

Severe primary IGF-1 deficiency (SPIGFD) is a medical term used when IGF-1 levels are extremely low or undetectable in the blood. IGF-1 is vital for the body as it regulates the growth-promoting effects of the body's growth hormone by acting on 'target' body tissues such as the growth plates of the bones.

The most recognised form of SPIGFD is a genetic condition called Laron syndrome. Patients with Laron syndrome have an abnormal growth hormone receptor (GHR) which does not function properly. The GHR is vital for normal growth, as it recognises and binds growth hormone, triggering the release of IGF-1 and stimulating growth in the individual cells of the body.



SHOX/Sotos Syndrome

SHOX Deficiency

SHOX Deficiency is a frequent cause of short stature. Human genes are made up of DNA and every person has two copies of each gene, one inherited from each parent. Genes act as instructions to make molecules called proteins and each protein has a specific function in the body. SHOX is a gene (short stature homeobox-containing gene), which plays an important role in bone growth and development. SHOX deficiency as a result of SHOX gene abnormalities causes poor growth in children, usually in the first few years of life.

Sotos Syndrome

Sotos Syndrome is a rare overgrowth condition that causes rapid growth in early childhood resulting in children being considerably taller than their peers. It affects around 1 in 10,000 newborn babies.

In around 90% of children with Sotos Syndrome the cause is a mutation in the NSD1 gene. This gene provides instructions for making a protein that is involved in normal growth and development.

Aside from the tall stature children with Sotos Syndrome are likely to

encounter a number of other difficulties and symptoms, including: scoliosis (curvature of the spine),



heart and kidney defects, hearing loss and problems with vision. People with Sotos Syndrome are prone to seizures and can have moderate to severe learning difficulties. They can also have behavioural issues including Autism, ADHD, phobias, obsessions and difficulties with speech and language.



TBRS/Weaver Syndrome/PSM

Tatton-Brown Rahman Syndrome

Tatton-Brown Rahman Syndrome (also known as DNMT3A overgrowth syndrome) is a syndrome that produces faster than normal growth both before and after birth. TBRS has very recently been discovered and it is still unknown exactly how many people it affects.

Children born with TBRS are likely to encounter a number of additional symptoms, aside from the overgrowth, including: a curving of the upper back, heart defects, flat feet, weak muscle tone and very loose, flexible joints. They may also have learning difficulties ranging from mild to severe and there is a high occurrence of difficulties with communication and social skills, similar to those of autism spectrum disorders.

Weaver Syndrome

Weaver Syndrome is an overgrowth syndrome similar to TBRS. A lot of the characteristics and symptoms are similar and it is unknown how many children are affected.

A main difference between Weaver Syndrome and TBRS is in the cause of

the syndrome. Weaver Syndrome is caused by a mutation in the EZH2 gene, this gene provides instructions for making an enzyme that modifies the proteins that structurally help the shape of the chromosomes.

Premature Sexual Maturation

Premature Sexual Maturation (PSM) is a condition that affects the gonads, adrenal and other glands causing premature sexual maturation. It is a general term and includes precocious puberty. The precise reason for the occurrence is unknown but the hypothalamus and pituitary gland signals the reproductive glands to start making hormones at an earlier than normal age.

Children with PSM and precocious puberty may be taller than their peers, but their growth stops at an earlier age, which means final height can be relatively short. In girls puberty can occur between the ages of 8 to 14 and in boys from 9 to 14. PSM would typically be signs of puberty prior to these ages.



How we help

The Child Growth Foundation has been delivering support to people affected by growth conditions for over 40 years.

Having a rare condition that people haven't heard of, often including health professionals, can be a daunting and isolating experience. This is why our support is so vital and gratefully received.

Each year we help around 1,500 families struggling to cope. We do this by:

**running a telephone
and email helpline**

**producing
information sheets and
guides**

**providing virtual
peer group supports**

**increasing
understanding among
health professionals**

**delivering an
annual convention that
provides information and
peer support**

**raising awareness
and understanding about
the conditions**

**funding research
into the causes,
identifiers and ways to
improve treatments**

"The convention is the one time out of the year that Clare does not feel different to everybody else and she enjoys that weekend so much."

"The support and information from the CGF is excellent."

"It was a very trying time waiting for a diagnosis...the Facebook group became a lifeline of support I would have been lost without it"



Annual Convention

The CGF Annual Convention is a weekend family event of information sharing and peer support and usually takes place in October each year.

The Convention enables members to learn about research updates, general management and treatment

**“VERY WELL ORGANISED
AND VERY BENEFICIAL TO
OUR FAMILY”**

strategies from health professionals and spend time with other families going through the same thing. This peer support element is one of the most beneficial elements of the weekend.



The Convention is only open to members of the charity, but membership is just £25 per year.

**“I ALWAYS COME AWAY
WITH MORE KNOWLEDGE
THAN I CAME WITH”**

Younger children are entertained and looked after by professional carers in the creche. Older children enjoy more age-appropriate activities including the games-zone and workshops.

Saturday evening is 'let your hair down' time, with a fancy-dress theme, entertainment, raffles, auctions and a buffet.

**“AN ALL ROUND
GREAT WEEKEND”**



Research/Awareness

Funding Research

The Child Growth Foundation provides funding for research to increase the understanding of, and provide improved treatment and support for growth conditions.

We are very proud of the research projects we have supported in the past and those we are currently involved with. In the last ten years we have provided over £1,000,000 in grants to researchers who are working to improve the lives of children, adults and families affected by growth conditions.

The funding of research is a top mission objective for the CGF and it is committed to providing regular research awards.

Supporting Healthcare Professionals

We aim to support the healthcare profession in the diagnosis, management and treatment of patients who have growth related conditions.

We achieve this by:

- ▶ delivering regular e-newsletters containing information and updates aimed specifically at health professionals



Springer Healthcare IME Webinar

- ▶ providing a telephone and email support line
- ▶ attending conferences and information days sharing the latest news on growth conditions
- ▶ assisting with the production of guidelines and consultations
- ▶ contributing to webinars and educational content

You can keep up to date with health professional updates by visiting our website and signing up to our e-news bulletins.

Awareness Raising

The conditions supported by the CGF are all rare conditions and therefore a lot of the work we undertake is to do with awareness raising to help increase understanding among the general public and professionals, that may encounter children and adults affected by growth conditions.



Common Questions

If my child is short/tall does it mean they have a growth condition?

No, there are many factors that can influence a child's growth. The chances of having a medical condition that will impact on your child's growth are extremely rare.

I am worried about my child's height, what can I do?

Talk to your GP, make sure regular measurements are being taken and that those measurements are consistent and accurate. If you feel there may be something wrong you can ask your GP to make an appointment to see a specialist (an Endocrinologist). The CGF can help you find your nearest specialist.

Is research being done to understand the conditions better?

Yes, a great deal of research is taking place, the CGF has been supporting research for over 40 years. There has also been increased understanding in the human genome and medical advances are taking place all the time.

Why don't you mention a cure?

Medical understanding may advance in the next few years where some growth conditions could benefit enormously, however, for some of the conditions we support the word 'cure' isn't even appropriate. For this reason, it is not a goal of the CGF to find a 'cure' for the conditions we support but to provide those affected, and their families, with the best support we can.

How can I support your work?

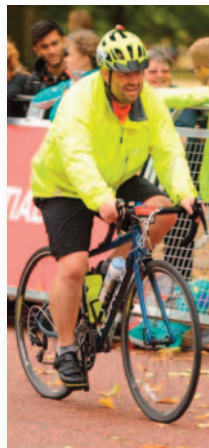
There is a section in this guide on how you can help and there is more information available on our website. You can contact us in any of the ways provided.

"IT'S THE MOST
AMAZING CHARITY!!"



How you can help

We exist to improve the lives of children, adults and families living with, and affected by growth conditions. Our work is vital. We



provide support, and hope, through the delivery of the services listed in this booklet, and yet there is so much more we need to be doing.

We receive no financial assistance from the government in support of our work

and exist by the generosity of donations.

Your support can make a huge difference.

There are a number of ways you can get involved:

One-off Donations/Standing Orders

Please consider making a donation to support our work today.

To make a donation you can either visit our Facebook page and click 'donate'

facebook.com/childgrowthfoundation

Or you can visit our website and donate through there:

childgrowthfoundation.org/donate

To set up a standing order, visit our website or call us on 0208 912 0723

Take part in a professionally organised fundraising event.

These happen all over the country and there are many types of events. To help you find one, email us at:

fundraising@childgrowthfoundation.org

Organise your own fundraising event.

From a cake and bake sale to swimming 100 lengths in your local pool, the options are almost limitless. There are more ideas on the fundraising pages and of our website.





Your support

Employer Support

Ask your employer if they have a charity of the month/year scheme and put our name forward. Or see if they offer a donation match scheme.

Awareness Raising

Another benefit of fundraising is the awareness it raises. Through fundraisers taking part in events the Child Growth Foundation is promoted and people find out who we are and what we do. We have been supported by some amazing fundraisers over recent years, who have taken part in the London Marathon, Vitality 10k, RideLondon and the Big Toddle. We are very grateful for every penny raised.



Corporate Support

Corporate support can have a huge impact on the work the CGF undertakes and by engaging with charities has been proven to help businesses by:

- + enhancing employee relations
- + creating a better public image
- + promotion of team building
- + improving employee retention

We are grateful to the businesses that have already supported our work and are always on the lookout for more mutually beneficial partnerships.

If you would like to find out more please contact us, or visit:

childgrowthfoundation.org/corporate-support



Membership

The Child Growth Foundation works to deliver outstanding support for families affected by growth conditions. It also funds research into the causes and treatments of growth conditions and it raises awareness and understanding of them among health professionals and the general public.

Part of the way we fund this work is through a membership scheme that provides further support and information. Membership to UK residents is just £25 per year and provides the following benefits:

- ▶ **Contact with other families affected by growth conditions**
- ▶ **Our twice-yearly newsletter packed with news, details of events, research and fundraising, and information on the conditions we cover**
- ▶ **The opportunity to attend our fantastic annual convention**
- ▶ **Access to our Members Only Portal**
- ▶ **Ask a health professional section**
- ▶ **Be part of the CGF family and help us provide support to families**

To join the Child Growth Foundation, please visit our website where an online application can be completed. Alternatively contact us and we will send you an application form.

info@childgrowthfoundation.org

0208 995 0257

**“IT IS SUCH A VALUABLE ORGANISATION,
ESPECIALLY FOR PARENTS OF CHILDREN THAT HAVE
JUST BEEN DIAGNOSED BECAUSE IT HELPS THEM TO
FEEL NOT SO ALONE IN THEIR SITUATION.”**



History of the CGF

The Early Years

The Child Growth Foundation (CGF) was founded in 1977 by Tam and Vreli Fry following a discussion between six sets of parents whose children were being treated at Great Ormond Street Hospital for a variety of growth conditions. The late Professor James Tanner, a senior endocrinologist, hoped a charity could be created to support his much-needed research into growth conditions. Through connections Tam Fry had at the BBC a television drama called 'Being Normal' was commissioned and transmitted in 1982. The drama starred David Suchet and Anna Carteret and highlighted the story of one of the parents' daughter, who had Growth Hormone Deficiency.

Growth Charts

In the 1980s, the CGF began training primary care staff in the importance of growth, and developed growth-monitoring equipment. In 1989, the CGF funded the development of the UK growth charts, which replaced charts that had been used since the 1960s. The charts were used in the Personal Child Health Records books, commonly known as 'the red book',

until 2010 when the Department of Health decided that the new World Health Organisation (WHO) growth charts should be used.

Funding Research

The revenue gained from the sale of growth monitoring equipment, and the royalties from the use of the growth charts, enabled the charity to operate, support families and fund research into growth related conditions for many years. Since the introduction of the WHO growth charts the CGF revenue has reduced considerably. This has directed the CGF to find other ways of raising much needed funds to enable it to continue to support families and fund research.

Today

Overheads are kept to a minimum, with just three part-time members of staff, who maintain the day to day running of the charity with a committee of volunteers. This comprises the Chair, Vice Chair, Treasurer, a group of Trustees and a small army of front-line support volunteers.



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