

A close-up photograph of a young child with blonde hair, smiling and showing their teeth. The image is overlaid with large, stylized, light blue and white abstract shapes that resemble a hand or a protective shield. In the top right corner, there is a circular logo with the text "SYNDROME DU DOWN ASSOCIATION" in a dark blue, sans-serif font, arranged in a circle.

SYNDROME DU
DOWN ASSOCIATION

DOWN SYNDROME ASSOCIATION

INFORMATIVE BOOKLET

A MESSAGE TO READERS

Dear readers,

As part of a collaborative project with the Faculty of Medicine and Health Sciences at the University of Sherbrooke, the Down Syndrome Association (DSA) is proud to present you with an informative booklet on Down Syndrome.

In this booklet, you will find multiple sections and resources that we hope will answer your questions, help guide you and answer your concerns, fears and insecurities. Whether you are a parent or family member, a guardian, a foster parent, a volunteer, a friend, or a person with Down Syndrome, you're at home with us!

AMONG OTHER THINGS, YOU'LL FIND THE FOLLOWING
DETACHABLES SECTIONS IN THIS BOOKLET :

- Trisomy 21 information kit
- Growth charts
- Testimonials
- Basic and specialized health care
- Services for new parents
- Financial and legal assistance
- Interesting and little-known facts about Down syndrome!
- Quebec government support guide
- General information about DSA
- Local resources
- DSA business card
- List of available resources
- DSA calendar of events
- The association's annual report
- Day camp registration forms
- FAQ

We thank you for your reading time and hope that this booklet will meet your needs!

- The Down Syndrome Association in collaboration with Mathis Lamoureux, Jonathan Jagermann, Henry Huynh, Thomas Steverman, Valérie Généreux, and Maxime Poirier, medical students at the Université de Sherbrooke.

* Note : This document, for educational purposes, provides a non-exhaustive overview of the scientific data currently gathered on Down syndrome. For further information, please refer to the resources provided at the end of this explanatory document.

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FIRST SECTION



DOWN SYNDROME

IN A FEW PAGES

THE TYPES OF TRISOMY 21

Also known as Down syndrome, trisomy 21 is a non-hereditary genetic condition that occurs when a person has an extra chromosome in their 21st chromosomal pair. This condition is quite common, with an average incidence of one in every 770 births worldwide.

Normally, the human genome contained in every cell of our body has 23 pairs of chromosomes, giving a total of 46 chromosomes. However, people living with trisomy 21 have 47 chromosomes, this difference being due to a congenital anomaly during embryonic development. Research has determined that this chromosomal anomaly, which is the result of non-disjunction, can take 3 different forms. Trisomy 21 is not a disease, but a condition, and there is no cure.

FREE TRISOMY

Affecting around 95% of people with trisomy 21, this is by far the most common form. It results from an error in chromosome distribution during the embryo's first cell division, with each cell in the body subsequently carrying an extra copy of chromosome 21. It is the additional presence of this chromosome that characterizes trisomy 21.

TRANSLOCATION TRISOMY

Accounting for around 3% of trisomy 21 cases, this form is distinguished from free trisomy by part of chromosome 21 detaching and attaching to another chromosome. This alters the genetic structure and can lead to a variety of presentations of trisomy 21. Parents who carry a translocated chromosome in their genetic make-up can check the risk of passing it on to their children by consulting a geneticist.

MOSAIC TRISOMY

Accounting for around the remaining 2% of the trisomy 21 population, some cells in the body have an extra copy of chromosome 21, while others have the normal number, known as mosaicism. This combination of cells with 46 chromosomes and cells with 47 chromosomes, which takes place during the second cell division, in some cases attenuates the physical traits and typical characteristics associated with trisomy 21. This contributes to the diversity of Trisomy 21 presentations.

THE PHYSICAL FEATURES

People living with Down Syndrome have distinctive physical characteristics that can vary from one person to another, creating a wealth of diversity. The most common feature is slanting eyes due to the presence of a thin layer of skin at the corner of the eye. There may also be a rounded face, a small skull, a flattened nose, low-set ears, thin lips, difficulty in controlling the muscles of the tongue, and other unique features such as shorter legs and arms. In general, people with Down syndrome have a smaller stature and lower muscle tone than the norm.



However, these physical characteristics do not define the whole person. Each individual is also recognizable by family hereditary traits. Furthermore, like every human being on earth, they develop their own personalities, making them uniquely their own. Recognizing and celebrating this diversity helps to promote deeper understanding and unconditional acceptance within society. It's crucial to remember that behind these physical characteristics lie people with a wide range of talents, interests and valuable contributions to offer.

PROGRESS AND DEVELOPMENT

Down syndrome influences a person’s development throughout their life, from pregnancy to old age. Understanding these different phases can help provide appropriate support at every stage along the way.

The following is a table of medical conditions frequently encountered in children with Down syndrome. These will be discussed in subsequent sections.

CONDITIONS	%	CONDITIONS	%
Hearing difficulties	75	Epilepsy	1 - 13
Vision problems	60	Blood-related issues	
Cataracts	15	Anemia	3
Refraction issues (require glasses)	50	Iron deficiency	10
Obstruction sleep apnea	50 - 75	Myeloproliferative syndromes	10
Otitis media (morphology of the eustachian tube)	50 - 70	Leukemia	1
Congenital heart disease/anomalies	40 - 50	Celiac disease	5
Delayed tooth breakthrough (dental agenesis)	23	Atlanto-axial instability (vertebrae C1 - C2)	1 - 2
Gastrointestinal atresia	12	Autism	1
Thyroid disorders	4 - 18	Hirschsprung’s disease	< 1

Table 1 : Frequent medical conditions in children with Down Syndrome

PREGNANCY

During pregnancy, Trisomy 21 can be detected by prenatal tests. This period is an opportunity for parents to get informed, prepare and discuss with health professionals to plan the care and support needed surrounding the birth of the child.

PRENATAL TESTING

In Quebec, prenatal screening for trisomy 21 is an important step for expectant mothers. Health professionals generally offer screening tests to pregnant women, particularly those aged 35 and over.

Advanced maternal age is the greatest identified risk factor for the development of trisomy 21. Nevertheless, the majority of affected babies are born to mothers under 35, due to the higher frequency of pregnancies at this age. Although there are factors that can influence the probability, it is essential to understand that trisomy 21 can affect any pregnant woman, whatever her origin, age or lifestyle.

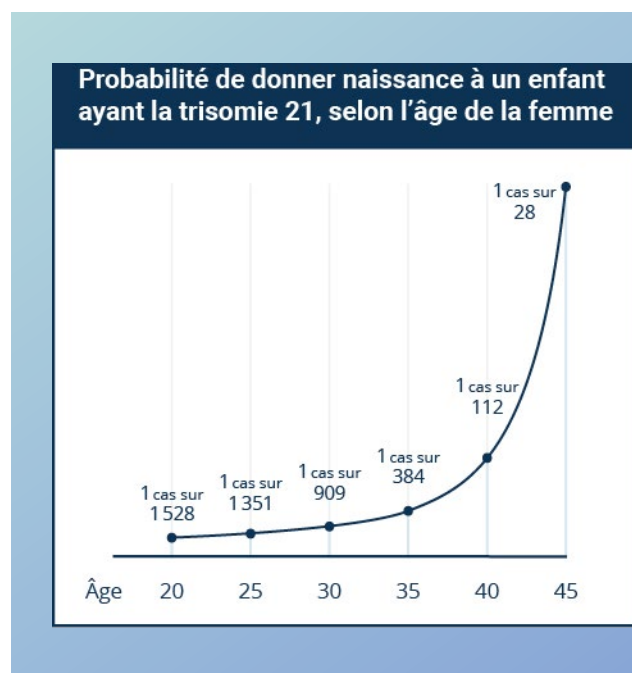


Figure 1 : [Fréquence de la trisomie 21](#)

THE MOST COMMON TESTS ARE :

- Nuchal translucency measurement at first-trimester ultrasound
- Non-invasive prenatal genomic testing (NIPT)
- Chorionic villus biopsy
- Amniocentesis

These tests assess the statistical risk of Trisomy 21, enabling future parents to make informed decisions about the continuation of their pregnancy. The test chosen will depend on the patient's choice, the doctor's recommendations and the patient's resources, as some such as NIPT involve costs.

Although these tests do not provide a definitive diagnosis, they do offer crucial information to guide families' choices. It's encouraging to see that Quebec is investing in early screening programs, thereby promoting maternal health and the well-being of future newborns. Medical teams are also there to support and advise parents throughout this process, using a respectful and understanding approach to the challenges of prenatal screening for trisomy 21.

When the parent decides to go ahead with the pregnancy, a plan is drawn up between the obstetrician and the family concerning the pregnancy follow-up, the various relevant tests and recommendations for consultation with sub-specialties such as pediatric cardiology, geneticists, endocrinologists and many others.

CARDIAC ANOMALIES

There are several complications associated with trisomy 21. Congenital heart anomalies are the most frequent, accounting for 40-50% of cases. Ultrasound screening for congenital heart anomalies is therefore performed routinely in pregnant women with children determined as having trisomy 21. This condition can present in a variety of ways, and has a major influence on patients' quality of life. In fact, congenital heart anomalies can necessitate frequent medical check-ups and even surgical interventions very early in the child's life, often accompanied by close and intensive medical follow-up for the whole of the patient's life. Life expectancy is also generally diminished.

The quality of life of patients suffering from a heart anomaly is often diminished, depending on the extent of the issue. This is why it is so important to consider whether the foetus has congenital heart anomalies when deciding whether to continue with a pregnancy, and why it is such an important factor for so many patients.

THE FIRST YEAR

At birth, babies with Down Syndrome may require special care, but with the right medical support, they can lead healthy, happy lives. Families can benefit from resources and support groups to help them understand and navigate the many challenges this condition brings.

As discussed at the beginning of this section, babies with Down Syndrome are at increased risk of multiple serious illnesses. Doctors in charge of the child will need to perform numerous tests to determine the risk of disease in the newborn.

TESTING

- **HYPOTONIA**, or low muscle tone, is often present in children with Down syndrome, and it's normal to notice that your child stands less easily on his or her limbs. This is nothing to worry about.
- **BREASTFEEDING PROBLEMS** are common in children with Down syndrome. Many of them will be able to feed properly with practice, but some will need supplementation. It's also important to mention that children with Down Syndrome often sleep much more than the norm, and it's necessary to wake them up in order to respect their feeding schedule.
- A cardiac ultrasound will be performed by a pediatric cardiologist, to detect **CARDIAC ANOMALIES** as mentioned above and correct them if necessary.
- A **CAR SEAT TEST** will be performed at the hospital to check whether the child is able to tolerate the car seat, and whether he or she has any heart or muscle tone problems that would interfere with its use.
- Several **BLOOD TESTS** will be carried out to check for possible haematological and thyroid disorders.
- Lower **RESPIRATORY INFECTIONS** are more frequent in babies affected by trisomy 21. They will be closely monitored from a medical point of view in order to introduce targeted and more aggressive treatments in this respect if necessary.

SERVICES

Services and therapies are valuable resources in the lives of both parents and children. They will enable the child to reach his or her full psychological and physical potential, while supporting the parents through processes. Their impact should not be underestimated and is a crucial part of a child's healthy development.

ALTERNATIVE TREATMENTS AND THERAPIES

Your doctor will probably discuss with you the alternative therapies that are available. There are many of them, and the evidence for their effectiveness is often not clear-cut nor scientifically established. Some are safer than others, but it's important to recognize and identify alternative treatments that will drain your financial resources without proven effectiveness, especially given the increased cost of living with a child with Down syndrome.

It's also particularly important to recognize alternative care that could be detrimental to your child's health. We recommend that you discuss with your doctor before seeking alternative care.

CHILDHOOD AND ADOLESCENCE

Childhood is a crucial period for development for all children, and this doesn't change for children with Down Syndrome. During childhood, children with Down syndrome benefit from inclusive education and support tailored to their needs. Individualized approaches, language development programs and social activities contribute to balanced development.

The care of children with Down's syndrome between the ages of 1 and 5 involves several stages, as these children are at greater risk of several medical conditions.



MEDICAL FOLLOW-UPS

- Frequent **BLOOD TESTING** ;
- Biannual assessments and follow-ups **VISUAL AND AUDITORY FUNCTION**. Recurrent ear infections, cataracts and refractive problems are very common in this population. This explains why monitoring these abilities is essential ;
- The search for **CARDIAC ANOMALIES**, as congenital heart problems are extremely common in this population ;
- Following the child's **PHYSICAL DEVELOPMENT** using growth curves ;
- Assessment of **HYGIENE** et hygiene autonomy ;
- **THYROID FUNCTION MONITORING** to ensure that thyroid function is not impaired, which is the case is in around 18% of children with Down's syndrome ;
- The search for symptoms of **CELIAC DISEASE**, present in more than 1 in 20 children with trisomy 21 ;
- The search for symptoms of **OBSTRUCTIVE SLEEP APNEA**. This condition is present in the majority of patients with trisomy 21, in whom treatment could improve their quality of life ;
- Information sessions providing advice on **HEALTHY EATING** and **EXERCISE PROGRAMS**, which are particularly important for improving children's overall health.

DISCUSSIONS TO HAVE WITH YOUR DOCTOR

- Discussion of the transition to preschool and **SPECIALIZED SCHOOLING** ;
- The child's **PSYCHOLOGICAL PROGRESS** throughout their development ;
- The child's **SOCIAL DEVELOPMENT** ;
- Development of the child's **AUTONOMY** and sense of responsibility ;
- The monitoring of **BEHAVIOR DISORDERS** at home and school that may occur during childhood and adolescence ;

- Guardianship and long-term **FINANCIAL PLANNING** from early adolescence, which is essential for the child's long-term care and decision-making ;
- Planning for the **TRANSITION TO ADULTHOOD**, including vocational training and job exploration, which is essential for increasing independence as an adult ;
- The possibility of **GROUP HOUSING**, independent living - the best type of housing to optimize their quality of life;
- Healthy **SEXUAL DEVELOPMENT** and behavior, including the need for contraception and the prevention of sexually transmitted diseases (more on this in the sexuality section) ;
- **PREVENTION** of smoking, alcohol and drug use ;
- Taking care of the **EMOTIONAL WELL-BEING** of parents and family. To take good care of your child, you must always take good care of yourself.



ADULTHOOD AND LATER STAGES OF LIFE (21 +)

In adulthood, support continues to play a key role in people with Down's. Educational and vocational programs tailored to individual skills can foster independence and social inclusion. Access to inclusive employment opportunities also contributes to fulfillment.

One of the biggest question marks for parents giving birth to a child with Down syndrome is the lack of autonomy that persists as the child ages. Down syndrome implies a lifelong commitment, often more so than with other children. Growing up, a gap may form between what is desired and what is observed in terms of social skills and self-sufficiency. Adults with Down Syndrome therefore often require long-term multidisciplinary support, particularly in the medical and psychosocial fields.

However, this does not mean that it is impossible for an adult with Down Syndrome to live a life like others, look after themselves and thrive. With rapidly evolving interventions and support, near-independence in adulthood is entirely conceivable. Because the syndrome is expressed along a spectrum, many people with Down's Syndrome will be able to leave home, hold a stable job and lead their adult lives with minimal support.

HOUSING

One challenge that some people with Down's can experience is that of living with one's parents for an extended period of time. While this is often necessary to provide the services needed for life and development, many people with Down syndrome decide to live alone, in homes offering home care and certain necessary services.

It's a delicate discussion to have, since major changes are likely to destabilize the person. However, with the consultation and support of health professionals such as occupational therapists, psycho-educators and social workers, they can achieve increased autonomy.

DECISION-MAKING ABILITY

Early cognitive deficiencies also pose a challenge for people with Down syndrome and their families. This can become a challenge for work, housing, aging, as well as romantic and sexual life.

It's important to prioritize the person's wishes and maximize their autonomy in decision-making, but also to support them and intervene on their behalf if, and only if, they are not fully capable of making decisions for themselves. Fortunately, this is a point of difficulty that healthcare professionals are equipped to address.

MEDICAL FOLLOW-UPS

In adulthood, as in childhood, annual medical check-ups are essential to identify emerging health problems so that the medical professionals can intervene accordingly, if necessary. See the table at the beginning of this section for more information on common health problems for people with Down's syndrome.

LIFE EXPECTANCY

The life expectancy for people with Down's Syndrome now averages over 50 years. It is therefore crucial to foster the development of autonomy in these individuals, in order to promote fulfillment in adulthood and lighten the workload of aging parents as much as possible.

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THE SOCIAL ASPECT

NATURAL SOCIAL BUTTERFLIES

People with Down syndrome, often referred to as «innate extroverts», demonstrate a strong affinity for social interaction, despite the language challenges they may encounter, especially in early childhood. Parents testify that their children express a palpable joy in interacting with their peers, whether at daycare or with other acquaintances. Although language can present obstacles, their ability to communicate is remarkable. But how do they do it?

LANGUAGE DEVELOPMENT

During the first year, the similarities with a neurotypical baby are striking. Communication is essentially non-verbal, expressed through adorable smiles and sometimes less pleasant cries. Unlike the autism spectrum, many Down syndrome children maintain eye contact and share their attention.

Although it may be different for some who may have comorbidities, such as autism spectrum disorder and intellectual disability, most prefer communication through facial expressions and gestures. Between the ages of 2 and 5, they point to express needs and use gestures to comment. At school, their language skills evolve, and they enjoy making others laugh with jokes and can carry conversations.



SPEECH

The acquisition of motor functions required for verbal communication can be challenging for people with Down syndrome due to motor limitations. This can lead to articulation difficulties. However, tools such as pictograms or sign language can facilitate communication. Early intervention, including consultation with a speech therapist, is recommended to improve language skills.

RICH IN DIFFERENCES

Each person with Down syndrome lives a unique experience and has a unique personality. Some individuals may present comorbidities requiring closer medical monitoring and specific interventions, whilst others will not. As a result, although some may encounter language barriers for a variety of reasons, children with Down syndrome are often very affectionate, loving, and enjoy sharing moments of laughter with their friends!

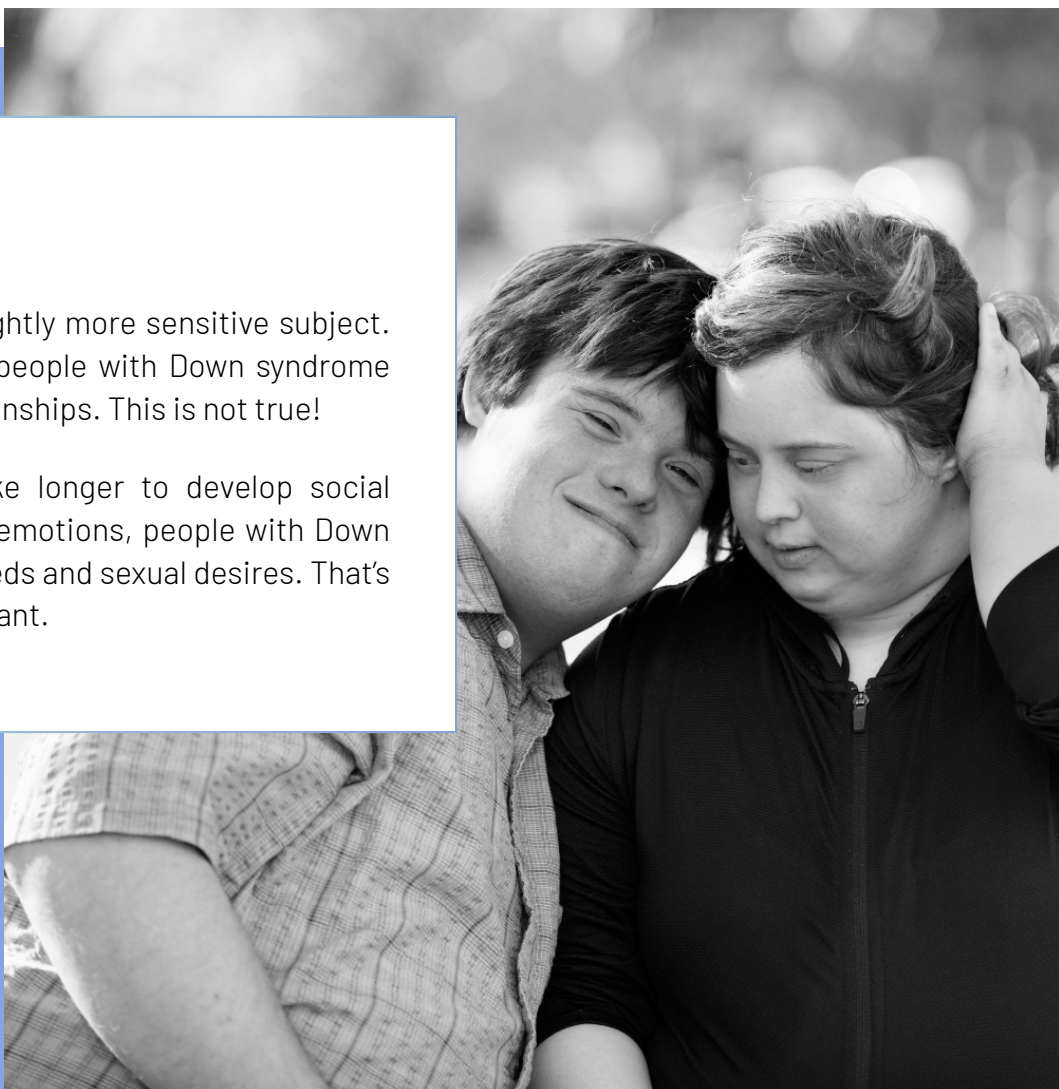
SOURCES

Available from: <https://www.dsrf.org/resources/information/communication/speech/>
Speech [Internet]. Down Syndrome Resource Foundation. [cited 2024 Jan 26].

SEXUALITY

In this section, we'll tackle a slightly more sensitive subject. Some people may believe that people with Down syndrome are incapable of romantic relationships. This is not true!

Despite the fact that they take longer to develop social maturity and control over their emotions, people with Down Syndrome still have intimate needs and sexual desires. That's why early education is so important.



SEXUAL EDUCATION

Education on what is acceptable and what is inappropriate as early as childhood and pre-adolescence is very important for your child's social development. This education needs to be individualized and adapted so that it is well understood by the child.

That's why a consultation with a health professional is highly recommended to help your child better understand all the changes to his or her body as well as their emotions, behaviors and new relationships that may develop.

USING PROTECTION

Condom use is a very useful tool among all sexually active people. Education about the risks of sexually transmitted infections is a very important issue that should be discussed during sex education.

Preventive education must be provided to protect people with Down Syndrome from the dangers that can occur in the home. Studies show that sexual vulnerability is more prevalent in this population since they are often unaware of the malicious intentions of some people, and sometimes have difficulty defining the limits of normal physical interactions. That's why teaching children to confide in others and showing them how to adequately assert themselves when needed, is essential.

In short, sex education is a topic that must be discussed because it is indispensable in your child's social development and health. It should start relatively early, be monitored by a health professional, and of course, be encouraged by parents.

SOURCES

Available from:
<https://ndss.org/resources/relationships-sexuality>
Relationships & Sexuality | National Down Syndrome
Society (NDSS) [Internet]. [cited 2024 Feb 23].

HEALTHCARE

BASIC CARE

Health care for people with Down syndrome is often multidisciplinary, focusing on overall support for physical and mental well-being. Healthcare professionals play an essential role in managing the special needs of these individuals.

Regular medical check-ups, follow-up programs and early intervention can contribute to the early detection and treatment of any health issues. Preventive care, such as vaccinations and dental check-ups, are also integral to ensuring optimal health.

SPECIALIZED CARE

PHYSIOTHERAPY

An essential component of care for people with Down syndrome is physiotherapy. It aims to improve gross motor skills, coordination and balance. Physiotherapists work closely with individuals and their families to design adapted exercise programs, and consequently promoting a better quality of life.

OCCUPATIONAL THERAPY

Occupational therapy focuses on improving functional skills and independence in daily activities. For people with Down syndrome, this can mean interventions to develop skills related to personal autonomy, such as dressing, eating and household tasks. Occupational therapists work closely with individuals to enhance their ability to participate actively and autonomously in daily life.

SPEECH THERAPY

Speech therapy plays a crucial role in the development of language and communication. Speech therapists work with people with Down Syndrome to improve pronunciation, vocabulary, comprehension and more. Interactive activities are also used to stimulate and encourage communication and strengthen language skills. .

PSYCHOEDUCATION

Psychoeducation aims to support the emotional and cognitive development of people with Down syndrome. Psychoeducators work with individuals to strengthen social, emotional and cognitive skills. They offer invaluable support in overcoming learning difficulties and other challenges, facilitating a smoother integration into society.

These specialized services, which are individualized for the unique needs of each person, help maximize their potential, help them overcome challenges and result in greater autonomy. The holistic approach of these interventions maximizes the quality of life of people with Down syndrome.

SOURCES

Accueil - asdet21 [Internet]. [cited 2024 Feb 28]. Available from: <https://www.asdet21.org/>



SECOND SECTION



GROWTH

CHARTS

GROWTH CHARTS

GIRLS 0 - 36 MONTHS

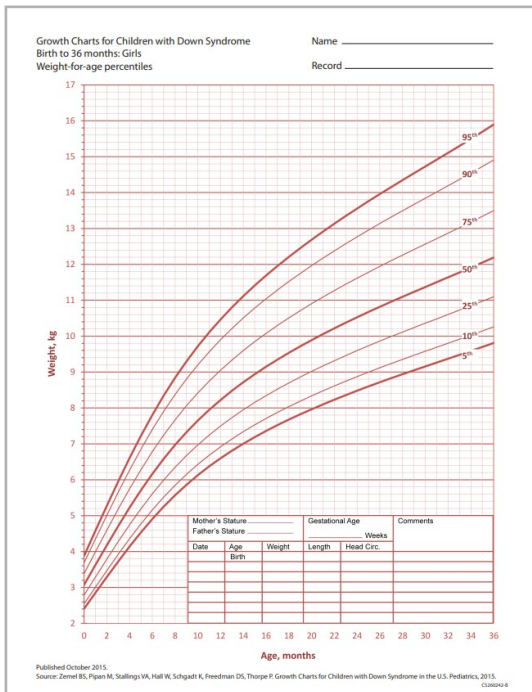


Figure 2 : Weight (kg) in relation to age (months)

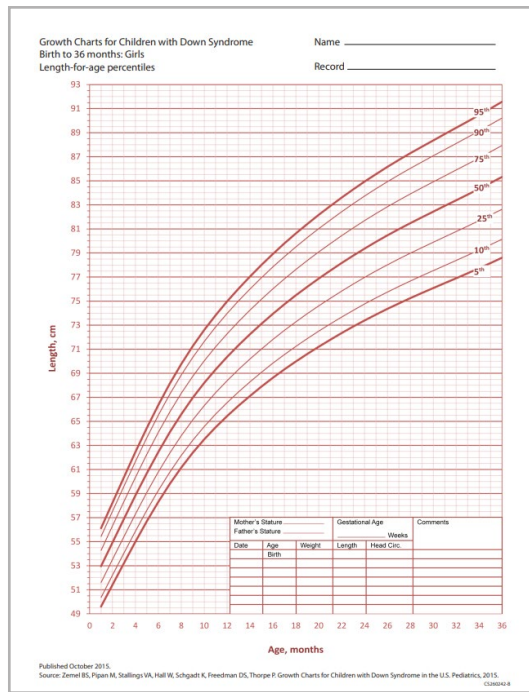


Figure 3: Height (cm) in relation to age (months)

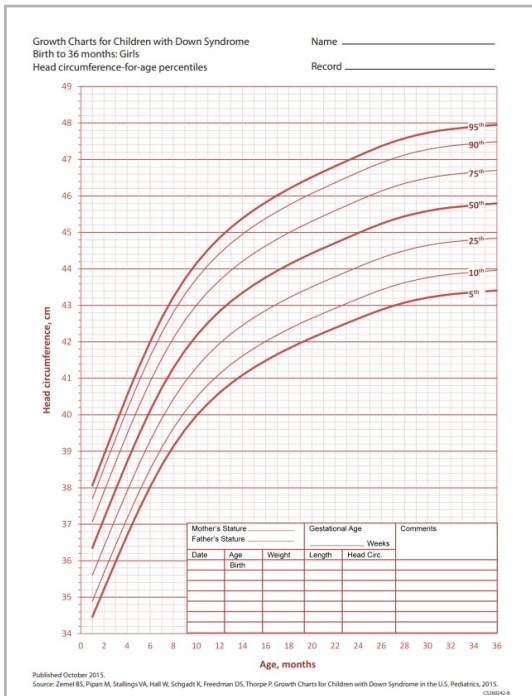


Figure 4 : Cranial circumference (cm) in relation to age (months)

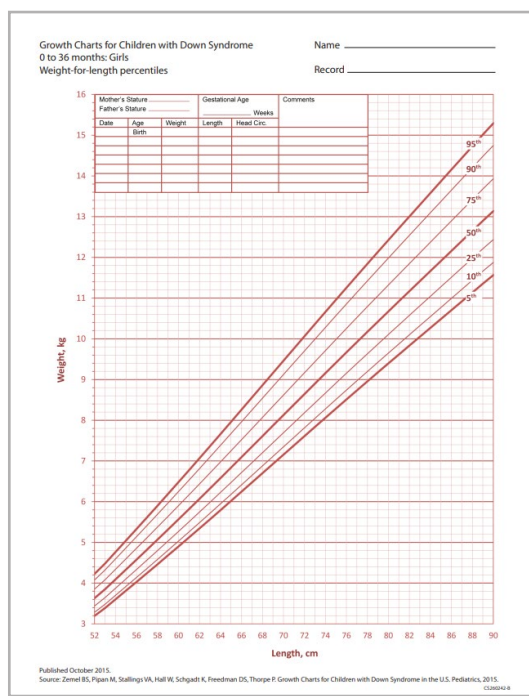


Figure 5 : Weight (kg) in relation to height (cm)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome | CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

*These curves can be consulted in the *annex* at the end of the document.

GROWTH CHARTS

BOYS 0 - 36 MONTHS

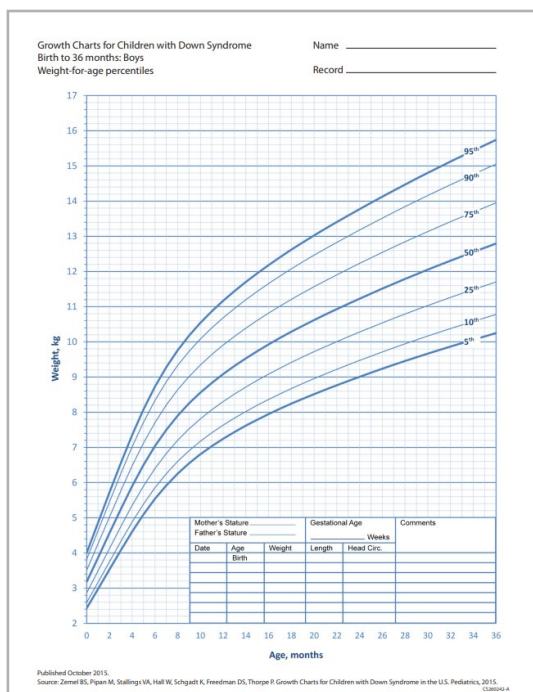


Figure 6 : Weight (kg) in relation to age (months)

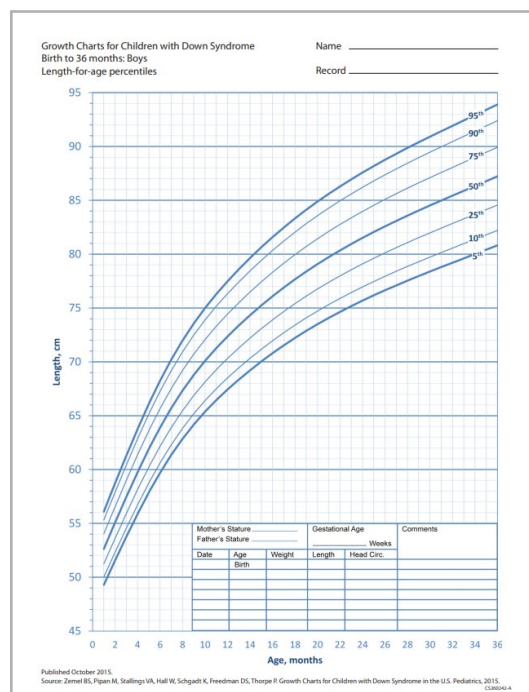


Figure 7 : Height (cm) in relation to age (months)

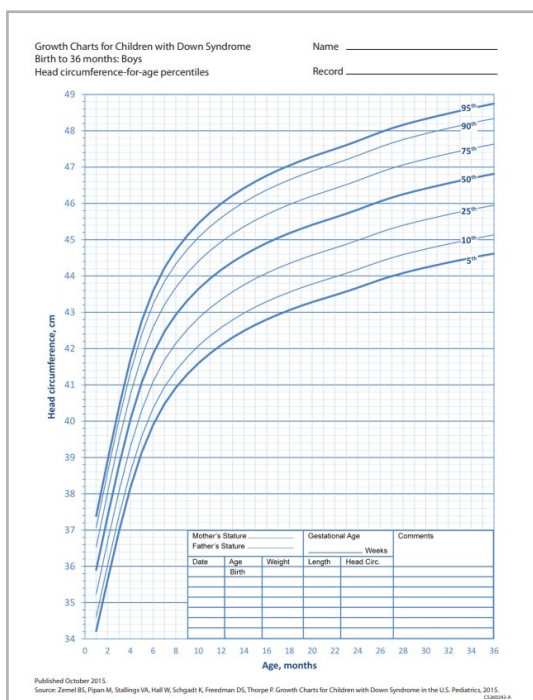


Figure 8 : Cranial circumference (cm) in relation to age (months)

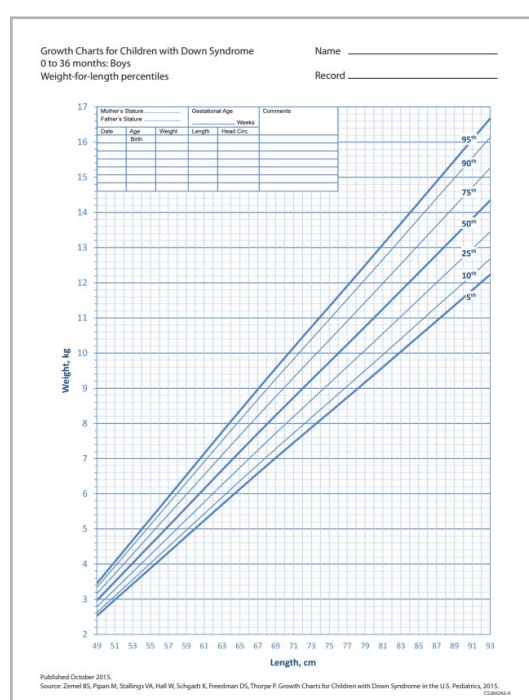


Figure 9 : Weight (kg) in relation to height (cm)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome |
CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

*These curves can be consulted in the annex at the end of the document.

GROWTH CHARTS

GIRLS 2 - 20 YEARS OLD

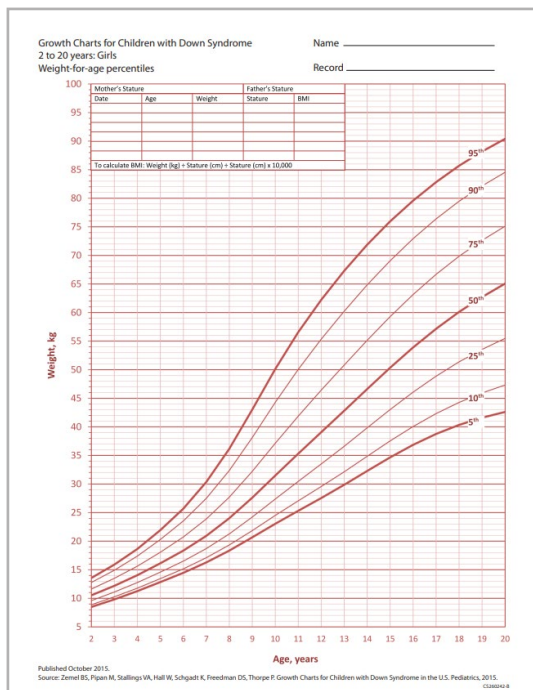


Figure 10 : Weight (kg) in relation to age (years)

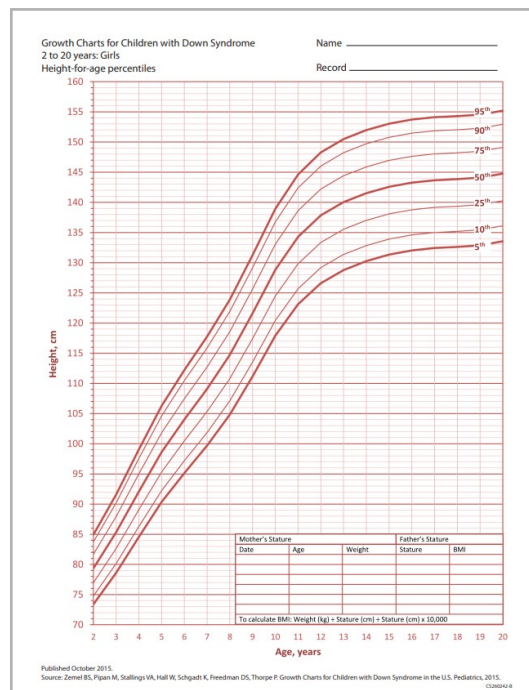


Figure 11 : Height (cm) in relation to age (years)

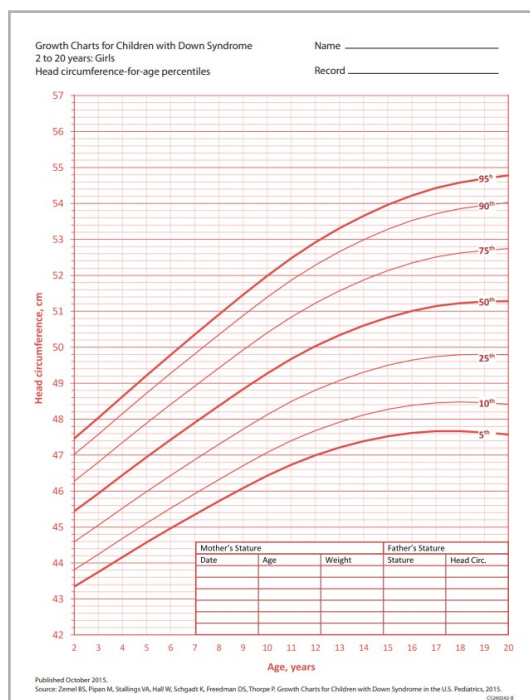


Figure 12 : Cranial circumference (cm) in relation to age (years)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome |
CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

*These curves can be consulted in the *annex* at the end of the document.

GROWTH CHARTS

BOYS 2 - 20 YEARS OLD

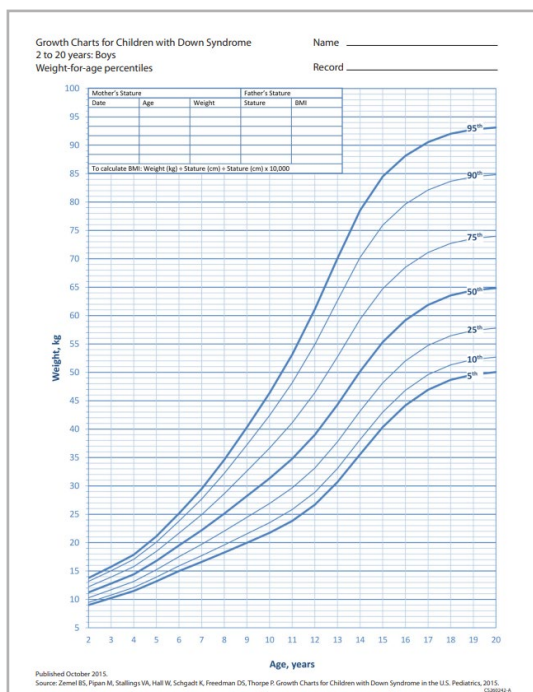


Figure 13 : Weight (kg) in relation to age (months)

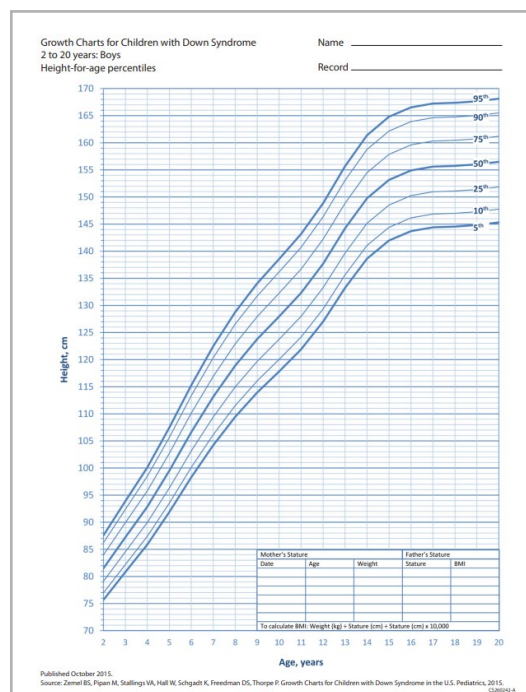


Figure 14 : Height (cm) in relation to age (years)

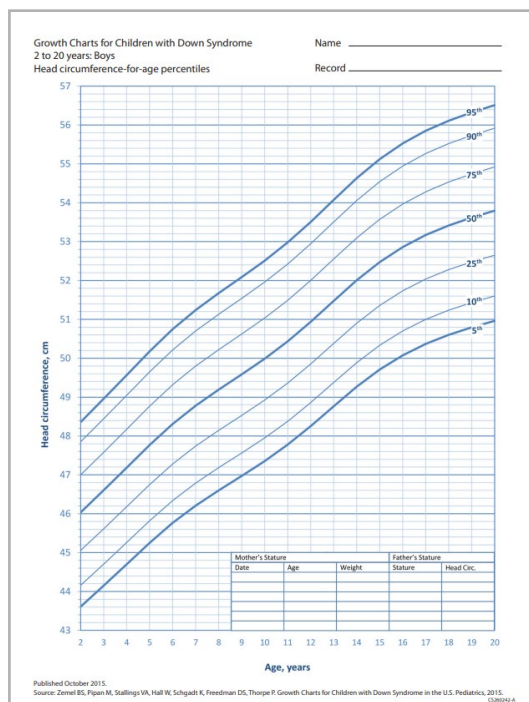


Figure 15 : Cranial circumference (cm) in relation to age (years)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome | CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

*These curves can be consulted in the annex at the end of the document.

THIRD SECTION



DOWN SYNDROME ASSOCIATION

MISSION, VALUES AND OBJECTIVES OF THE ASSOCIATION

MISSION

The Down Syndrome Association (DSA) is a regional non-profit organization (NPO) that has been working to improve the quality of life, integration and social participation of people with Down syndrome and their families since 1987. It was created by parents, who still represent a major strength of the movement today.

OBJECTIVES

- To promote health and alleviate associated conditions for people with Down syndrome by offering various workshops and activities aimed at the social, educational and professional development of beneficiaries.
- Promote health by offering a comprehensive support service to families of people with Down syndrome.
- Promote participation and integration on the social front of people with Down syndrome, their families and community members within the association.

The Association also represents a living space that promotes health and fosters the development of our clientele. The organization of activities breaks isolation and develops a sense of belonging.

VALUES HUMANITY

Being human means showing respect, compassion, benevolence, empathy, consideration and authenticity. Humanity means recognizing people's dignity, their ability to act, their right to express their choices, as well as their right to justice, equity and confidentiality.

COMMUNICATION

To receive accurate, timely and progressive information. To be able to express oneself according to one's abilities. Effective communication is about respect, listening and empathy.

VALORISATION

It's about recognizing the other person's entity and abilities, as well as demonstrating recognition for others' contributions.

SOLIDARITY

Joining forces to be stronger, helping each other to be more efficient and teaming up to do better. It means being open to others, their ideas and their values.

BOARD AND STAFF'S VISION OF DSA

In 2025, as it has been for many years, the Down Syndrome Association will be a place where human warmth, sharing and a deep respect for people prevail. A place where learning activities, pursuit of leisure and the development of personal skills and abilities will be carried out in complete safety, in line with the evolution of individual and collective needs.

Members will have access to a space large enough and functional enough to accommodate a variety of activities to suit their needs, according to their age group and personal interests. There will also be large, bright and sunny spaces including a kitchenette, appropriate activity rooms, a relaxation area, offices and 2 washrooms.

Our clients will have access to diversified programming covering healthy lifestyles (nutrition and physical activities), social skills development, work and leisure, all in a welcoming and stimulating environment. A backyard will provide safe access to a play area, swings, garden and patio; alternatively, proximity to a park will enable quick access to outdoor activities.

Everyone (people with Down syndrome, parents, families, friends, volunteers, workers) will feel that they have their place and importance within the association. All will be consulted and will be able to participate in the development of their organization. Employees, management, and the Board of Directors will work together, respecting each other's roles and functions. They will work in partnership with local organizations to offer their members ever more and ever better services.

So, the Association will be a stimulating, pleasant living environment ... a home for living, a home for autonomy ... where pleasure is the name of the game!!!

RECOGNITION BY THE MINISTRY OF HEALTH AND SOCIAL

The ASD is recognized as a supportive living environment in the community by Quebec's Ministry of Health and Social Services (MSSS).

A LIVING ENVIRONMENT IS DEFINED AS :

- A place of belonging and transition
- A network for mutual support and action

ASD is an organization serving a targeted community, reaching out not only to people in difficulty, but to larger groups of people sharing common characteristics.

The organization has premises to welcome people and can even intervene in the communities' natural living environment.

THE ACTIVITIES, ALTHOUGH VERY DIVERSIFIED, OFFER SUPPORT SERVICES THAT CAN BE GROUPED AS FOLLOWS :

- Educational
- Collective
- Promotional and preventive

MEMBERS OF THE BOARD OF DIRECTORS

The Board of Directors is made up of 7 to 9 people, 3 of whom hold office: President, Vice-President and Secretary-Treasurer. Seven other people complete the Board as administrators.

Anyone wishing to join the Board of Directors should consult the organization's by-laws, as well as a document detailing the roles, mandates and responsibilities of an administrator, depending on the position held. This also implies engaging one's personal responsibility towards the various decisions made. The Board meets 10 to 12 times a year to deal with various issues concerning the management of the organization.

TEAM

THE ADMINISTRATORS OF THE DSA 2023 - 2024

Pierrette Therrien-Fernet, president
Marc Sweeney, vice-president
Josianne Lehoux, secretary-treasurer
William Fraser, administrator
Yannick Boisvert-Boucher, administrator

RESPONSIBLE TEAM FOR ACTIVITIES

Louise Meunier, general manager
Lucie L'Heureux, service coordinator
Rachel Dubuc, Interventionist for socio-professional and occupational activities
Gaétan Bérubé, responsible for chocolatri21 and interventionist for socio-professional activities

MEMBERSHIP AND CONTRIBUTION TO THE ASSOCIATION

You will need to fill out a membership application form, which you can find on the association's website at www.asdet21.org, and return it along with the payment of your membership card.

BENEFITS OF MEMBERSHIP

- Discounts on various activities
- Invitation to various activities
- Direct involvement in organizing activities

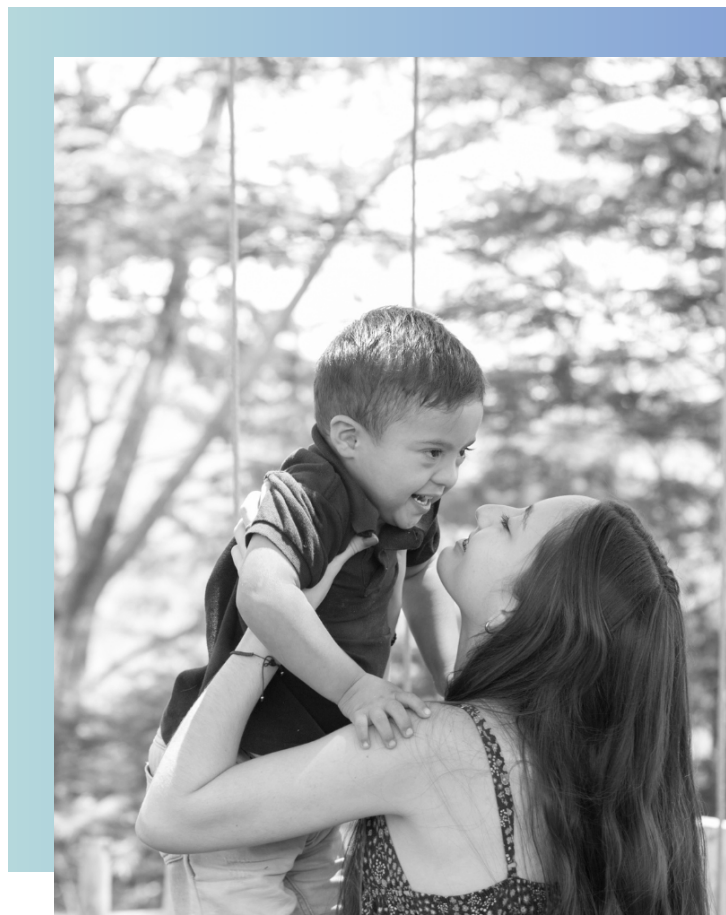
Becoming a member of the Down Syndrome Association means helping us in a concrete way to offer appropriate services to people living with Down syndrome and their families.

COST OF JOINING THE ASSOCIATION : 25\$ FOR 2 YEARS

MULTICULTURALISM

Trisomy 21 knows no borders, and neither does the Down Syndrome Association! In fact, the Association is welcoming more and more allophone members (including those speaking Spanish and Arabic, among many others), in addition to the region's French and English speakers, to offer a helping hand to everyone who can benefit from it, whatever their origins, language or culture.

The Association's programs and activities are constantly being revised to better meet the needs of all families affected by Down Syndrome, with a particular focus on the inclusion of new families in the Eastern Townships.



SERVICES FOR NEW MEMBERS

The needs of those who partake in the association are many. Whether you need a listening ear, support, information or referrals, a form filled out or your interests defended, ASD is there to help you and meet your needs more than ever!

WELCOME AND REFERENCE

The Down Syndrome Association welcomes you, offering attentive and supportive listening through telephone support, individual meetings and much more. This service allows you to ventilate, ask questions, share your experiences and guide you towards actions to take or resources to utilize, all while accompanying you in your steps. This service is available to parents, foster carers and people with Down syndrome.

OUTINGS AND WORKSHOPS

SOCIAL AND FAMILY CELEBRATIONS

Throughout the year, the association organizes family events such as Christmas parties and picnics. These are open to the whole extended family, including grandparents, parents, siblings and anyone else who wants to come along! Other family activities are added throughout the year.

SPECIAL OUTINGS

Special outings for people with Down syndrome and their families are organized throughout the year. For example, a visit to a tourist site, apple picking, an outdoors day, an outing to the sugar shack, and much more!

THEMED AND EDUCATIONAL WORKSHOPS

Our workshops offer educational and leisure activities for people with Down syndrome while providing respite for their families. The workshops aim to develop their life skills and abilities, self-esteem and autonomy. In addition, the organization promotes integration, socialization and personal valorization.

COMMUNITY WORK PLATEAUS (21 YEARS OLD AND +)

The association has set up a socio-professional work platform for young adults with special needs who have Down syndrome or an intellectual disability. The program covers every stage of the chocolate-making process, from production and packaging to online and retail sales with the participants.

CONFERENCES WITH PROFESSIONALS

Every year, several presentations are offered to parent members of the Association. The topics chosen are those previously expressed by parents.

SOCIAL GATHERINGS

Parents can get together to meet other parents; for example, by organizing evenings for moms and dads, or resource parents.

RESPIRE

DAY OR EVENING RESPIRE

Respite periods are offered during the day or evening, on weekends or on ped days throughout the year. These periods allow parents to have some free time. Space is limited and reservations must be made in advance.

RESPIRE CARE

The association wishes to help families with a T21 child and will soon be developing a respite care project for its members. This project will involve friends of the organization who will offer respite or occasional help by welcoming people with Down Syndrome into their homes. It will work by pairing up parents with Down syndrome children. Project under development.



INTER-FAMILY PARTNERSHIPS

It is also possible for new parents to be matched with other families who have a member actively living with Down Syndrome. These partnership arrangements enable families to exchange information, support each other in their different ways of functioning, and share the resources they have consulted to ensure a good quality of life.

SUMMER DAY CAMPS IN SHERBOOKE AND MAGOG

Every year, the Association offers a summer day camp for people with Down Syndrome in Sherbrooke. Several counsellors are on hand to cater to this clientele. In Magog, a counsellor associated with the Han Droits Organization for Down syndrome clientele offers services for that region.

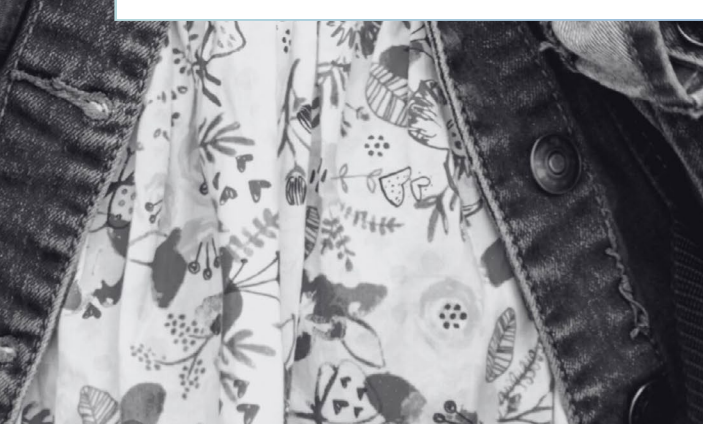
The animation team comes from a variety of educational backgrounds, including special education, social work, psychology and psycho-education. To ensure a safe, pleasant and constructive environment, the ratio is at least 3 youth per animator.

LIBRARY, VIDEO LIBRARY, JOUJOUTHÈQUE AND SPORTS FACILITIES

The association lends books, films, toys and sports equipment, according to the needs of its customers.

SOURCES

Accueil - asdet21 [Internet]. [cited 2024 Feb 28]. Available from: <https://www.asdet21.org/>



FINANCIAL AND LEGAL ASSISTANCE

There are a number of financial resources available to you, including government allowances and benefits.

If you are a family member or legal guardian of a child requiring extra care that obligates you to take time off work, you may be eligible for employment insurance. The application is done quickly online, and the necessary documents can be provided afterwards.

You may also be eligible for the [disability tax credit](#). As a result of this application, the amount of income tax you have to pay may be reduced to offset the costs of care and activities that enhance the quality of life of the person living with the disability.

If you are eligible for the disability tax credit, the [Registered Disability Savings Plan](#) is another option. This contribution is not tax-deductible, and payments are possible up to the last beneficiary year after age 59. These contributions are intended as an option to help people who want to save to ensure long-term financial security for the person eligible for the disability tax credit,

The [supplement for handicapped children](#) is available to people eligible for the [Family Allowance](#) who are responsible for a child under 18 and whose impaired mental functions prevent him or her from carrying out normal living habits for more than a year. These habits include nutrition, personal care, mobility, communication, interpersonal relations, responsibility and education. Subscribing to this supplement allows families to receive a fixed, tax-free payment of \$218/month. What's more, if your child requires complex medical care at home, and you have specialized training to administer care, you may be able to receive a supplement depending on the complexity of the child's medical condition;

If you qualify for the Canada Child Allowance (CCA) and your child qualifies for the Disability Tax Credit (DTC), you may be eligible for the [Child Disability Benefit \(CDB\)](#). This benefit is a tax-free monthly payment available to families with a child under age 18 who has a severe physical or mental impairment.

Finally, it is also possible to receive [«companion-leisure» cards](#), which enable disabled people and their companions to take part in recreational activities in their community without having to pay extra for the companion's admission.

FOURTH SECTION



TESTIMONIALS

TESTIMONIALS

TRISOMY 21, FROM THE VIEWPOINT OF SUCCESS!

— JOSÉE PERREAULT

*Please note that this testimony is from 2 years ago.

I am the mother of Jacob, 15 years old and a powerful teenager. He came into the world without us suspecting that he was different. It was during childbirth that we realized that our lives had veered off the course we thought we'd set. It was a shock, followed by a second shock in the first few hours of life: trisomy hadn't been the only thing to come along, there was also Fallot's tetralogy... In other words, four heart defects that require open-heart surgery within the first year of life.

Being knocked out twice in such a short span of time is a lot for new parents. But when faced with an ordeal, you have two choices: give up and collapse, or roll up your sleeves and move on. Within 15 minutes of the Down syndrome announcement, we had already chosen the second option. We didn't know how we'd do it, but one thing was certain: we would take action.

I will skip all the details, but Jacob had successful open-heart surgery at 4 and a half months. He's doing very well. He's a lively, imaginative, inquisitive, joking guy who loves music of all kinds. He has many dreams: a girlfriend, living in an apartment, driving, working and hosting The Voice or Star Académie!

Neither his nor our route is linear; he walked later, uses an adapted bicycle, and we can't really leave him alone at home. He's a chatterbox, but unfortunately most people don't understand him because he has a lot of language difficulties and he's impulsive.

I won't lie to you and say that our daily lives are easy; it's very demanding, the battles with the system are heavy, and we often feel exhausted. But each step forward stimulates us to keep going, because we want him to blossom and be happy.



Trisomy 21 often comes with other challenges that accumulate over time. In his case, it comes with a mild intellectual disability, ADHD, a severe language disorder, motor dyspraxia and, less than three years ago, a diagnosis of Autism Spectrum Disorder. I like to think that Jacob would be an excellent spokesperson for many causes, he would do a fine job!

All kidding aside, each diagnosis is nothing like the shock of being diagnosed with Down Syndrome at birth. Over time, we've come to understand that diagnoses don't undo him; he remains the same person, with the same qualities and the same challenges. It simply teaches us new ways of intervening and getting to know him better. But I don't want to dwell on what it's like to live with a disabled child, or how cumbersome the system is, or how much energy we have to devote to our child. I'd rather talk about the future.

Because, in addition to being Jacob's mother, I work at the Faculty of Law at the University of Sherbrooke, where I run the Professional Development Centre. In other words, I support law students in their skills development and try to prepare them as well as possible for their arrival on the job market. It's a funny paradox... I'm working with brilliant students with great potential, while at home, I'm the mother of a special-needs child with an intellectual disability for whom I don't know if he'll have a place in the job market.

While thinking about the notion of success that I wanted to talk to law students about, I came to a startling conclusion: The best example of success I can think of is Jacob.

Now you may be wondering how I can rhyme the words success and Down Syndrome or handicap..... In my research, I've realized that true success isn't about IQ, nor is it about being able to learn quickly, nor even being in good health. No. A successful person is one who is passionate and perseverant, one who gets up after they fall and makes the required efforts to achieve their long term goals.



Long-term goals and perseverance... that's what disabled people are all about! That's exactly what we teach our children every day, and let's face it, we're really talking about the long term here... So Jacob is the best example of success I can give to my students. He has to persevere to do everything in his life; it's by putting the effort in every day that he succeeds, and it's by stumbling and getting up again that he learns. With his unique personality and character, he's probably more successful than most neurotypical people who experience far fewer obstacles and take things for granted.

Let's stop going 100 miles an hour each on our own, and let ourselves be inspired by people with special needs who have an uphill battle. Jacob wouldn't evolve in the same way if he were left to his own devices, we're well aware of that. We're part of a team with him. Having parents who roll up their sleeves is important, but so is the rest of the team.

Resources like ASD and other groups, the Office des personnes handicapées du Québec, pediatricians and all the specialists, the Centre de réadaptation, CRDI, private specialists, the school, the family and so on... all these people, when you succeed in teaming up together, it makes a huge difference. As they say, as a team we are stronger and we go further... and I'd add that that's where success lies. Teamwork is everything.

The fear of all parents of disabled children is to know what's going to happen to our children when we're no longer there. Jacob is an only child, and I don't just want to know who's going to take care of him. I want to know who's going to have concern for him.

My message is **LEST'S TEAM UP!** My hat goes off to the people who get involved with people with special needs and commit to being a part of the team in their own way. We need to appeal to the generation that I'm lucky enough to work with on a daily basis at the University. This generation allows me to believe in the future for my son. They advocate equality and integration, they seek to break down barriers, they want a more balanced life, they are caring. I am under the impression that if we reach out to them, many of them are willing to team up with us and raise standards for our children.

These young people give me confidence that our children will be well supported in society, because they are our leaders of tomorrow. Now is the time to reach out to them. For a parent, it's essential to have confidence in the future.

When Jacob was born, I would have liked to have been told that he would do things differently, and that he would be well cared for. I wish that the way we look at difference is one that evokes possibility and benevolence, not pity and incapacity. When society sees people with special needs as having full potential, and learns to work with them and include them in the team, then we'll be able to say that society as a whole is successful.

I'd like to take this opportunity to raise a few questions: how do we look at disability? What more can we do to reach out to people with Down syndrome? How can we transform the term «vulnerable people» into positive terms? We tend to stop at a person's disability or diagnosis and put them in a box. Society would benefit so much from seeing our children's potential and strengths realistically, and putting them to good use. The Jacobs of this world are not so different from you and me; they just want to be happy and to be chosen as part of a team.

TESTIMONIALS

HOW ABOUT WE TALK ABOUT CHARLOTTE – PIERRETTE DENAULT

She has a lovely round face, mischievous little eyes and a heart-shaped mouth. She bites into life. She adores Sam, a wriggly, playful cocker spaniel, loves sports (baseball, field hockey) and music. Just by seeing the sparkle in her mother's eyes when she talks about her daughter, you can be sure that this teenager isn't short on love. Charlotte is a big girl of 12 with Down syndrome.

THE SHOCK

Nothing had prepared Josianne for this shock. When she was told the day after giving birth that her baby had Down Syndrome, she was furious. Why her? What had she done «wrong» to deserve this? Thanks to the support of her parents, her brother and her friends, the young mother got through this period with determination.

She was going to hang in there, bounce back and seek help. She had to overcome her feelings of guilt. Charlotte was HER daughter, she would ALWAYS be a different child, and she promised her unconditional love.



DAILY CHALLENGES



At first, the hardest part was seeing the judgment in other people's eyes. Sometimes there were even disparaging comments. But now, most of the time, people are benevolent. It has to be said that, wherever she goes, Charlotte is the center of attention and is well liked. Her mother believes that society has evolved, and that by talking about non-standard children, taboos are broken.

However, day-to-day challenges are numerous. For example, where to find speech therapy services? Where do you find the financial support to send your child to a specialized camp, which would give your mother some respite? The mental burden is enormous for parents of different children. Without wanting to look too far ahead, they are nevertheless concerned about their daughter's future. To ensure her daughter's safety, Josianne even made provisions in her will in case she passes before Charlotte; a gesture that has given her a great deal of peace of mind.

DAY BY DAY

Now, the mother no longer makes long-term plans for her daughter. She's learning to live in the moment, and takes every bit of progress Charlotte makes as a gift of life. Using a tablet to play music, showering alone, buttoning her pyjamas correctly: what seems like nothing for an average 12-year-old is a victory for her daughter.

At Le Touret school, she is learning to be independent and to make friends. Josianne is truly grateful for her family, who are always there when she needs them. Her only wish: for Charlotte to be happy, and that one day she will be able to fulfill her potential with a job that matches her abilities.



FIFTH SECTION



INTERESTING

FACTS AND FAQ

MYTHS AND INTERESTING FACTS ABOUT TRISOMY 21

1. Contrary to common beliefs, children with Down syndrome bring many benefits to the family; several studies show that families of children with Down Syndrome have a lower divorce rates and higher levels of tolerance and compassion among siblings.
2. In recent years, more and more adults with Down syndrome are living independently, with little or no family or government support. This is the result of increased sensitivity and inclusivity of the general public towards people with Down syndrome, as well as the introduction of support programs enabling these people to complete their education, hold a job and participate in leisure and social activities.
3. A common misconception about people with Down's syndrome concerns their ability to form loving relationships and have children. In reality, a good proportion of people with Down syndrome have close relationships, get married and some can have children*. What's more, their children are no more at risk of having Down syndrome, since trisomy 21 has a negligible hereditary component (~1%, only observable in translocation trisomies).
*Several studies have demonstrated the sterility of men with trisomy 21. However, these studies are under review, since several cases of men with the syndrome having children have been observed. Women with Down's syndrome are usually completely fertile.
4. People tend to believe that the life expectancy of people with Down Syndrome is very limited. Similar to the general population, the lifespan of people with Trisomy 21 varies greatly, but life expectancy is around 60 years. Some will live more than 80! It's true that in the past, their life expectancy was significantly reduced, but with the help of medical training and intervention, as well as community organizations like the Down Syndrome Association here in Sherbrooke, they now have the opportunity to live a full, fulfilling life.

SOURCES

Accueil - asdet21 [Internet]. [cited 2024 Feb 28]. Available from: <https://www.asdet21.org/>
Les témoignages ont été donnés par l'Association du Syndrome de Down

FAQ

IS DOWN SYNDROME HEREDITARY?

Down Syndrome is not hereditary. It is the result of a chromosomal anomaly that occurs during the formation of reproductive cells in men and women. During cell division and the formation of gametes, i.e. sperm and eggs, an error happens, resulting in an extra copy of the 21st chromosome. There is a type of trisomy 21, called translocation, which has genetic sources, but these cases account for less than 1%.

ARE THERE A CURE OR A TREATMENT FOR DOWN SYNDROME?

No, there is no cure for Trisomy 21, as it is a genetic condition. However, interventions to treat congenital malformations, as well as regular medical follow-up and the use of community resources, can contribute to a person's overall health and maximize his or her development.

WHAT ARE THE MOST COMMON MEDICAL ISSUES AMONG PEOPLE WITH TRISOMY 21?

Children with Trisomy 21 are at greater risk than the general population for a number of medical issues. In particular, congenital heart defects, respiratory problems, thyroid conditions and audiovisual difficulties are more common in these children, but are generally well managed by specialized medical care. Cognitively, they have delays that can express themselves as intellectual impairment, therefore, optimizing their education is essential to maximize their abilities.

ARE THERE « LEVELS » OF SEVERITY FOR PEOPLE WITH TRISOMY 21?

There are no distinct «levels» of severity for people with Trisomy 21, but each person's physical characteristics, strengths, weaknesses and abilities are different. For example, some may have relatively few physical characteristics, but experience greater cognitive difficulties, or vice versa. Trisomy 21 contains a spectrum of possibilities and differences, making each person unique in their developmental journey.

WHAT ARE THE PHYSICAL CHARACTERISTICS OF SOMEONE WITH DOWN SYNDROME?

Typical physical characteristics are: a small head, a flat face, almond-shaped eyes slanted upwards, a short neck, small round ears, small hands and feet, a single palm crease, short stature, and many others detailed in a previous section.

CAN SOMEONE WITH DOWN SYNDROME GET A DRIVER'S LICENSE?

Absolutely! However, they must pass Quebec's driving tests like everyone else.

WHY IS IT CALLED DOWN SYNDROME?

Dr John Langdon Haydon Down was the first to define and describe Trisomy 21, and for this, the genetic condition bears his name.

CAN SOMEONE WITH DOWN SYNDROME GET A JOB?

Yes, people with Down syndrome have impressive abilities! Employment corresponding to each person's capabilities and limits is encouraged!

WHAT IS THE LIFE EXPECTANCY OF SOMEONE WITH DOWN SYNDROME?

The life expectancy of someone born with Down syndrome today is 60 years old

WILL CHILDREN WITH DOWN SYNDROME DEVELOP SPEECH LATER?

On average, children with Trisomy 21 will start talking a few months later than the neurotypical population. However, with speech therapy, they can develop excellent communication skills when given the time they need to learn at their own pace.

CAN SIBLINGS CONTRIBUTE TO THE WELL-BEING OF A PERSON WITH DOWN SYNDROME?

Absolutely, siblings play a crucial role in the life of a person with Down syndrome and can contribute considerably to their well-being. The sibling relationship can be an invaluable source of emotional support, friendship and mutual enrichment.

Siblings can share moments of joy, complicity and learning with the person with Down syndrome. They can be natural allies in creating an atmosphere of inclusion, contributing to their sibling's social and emotional development. Shared experiences can strengthen family bonds and foster a deeper understanding of diversity.

However, it's important to recognize that there can be potential negative impacts.

At times, siblings may experience additional responsibilities or complex feelings related to their sibling's unique situation. They may face emotional or social challenges, such as the need to defend or explain their sibling's difference to their peers.

It's crucial for parents and relatives to ensure that siblings also receive the support they need. Open discussions, effective communication within the family and, if necessary, the use of support resources can help to mitigate negative impacts and promote a harmonious family environment where everyone can flourish.



SOURCES

Down Syndrome Answers. Canadian Down Syndrome Society. Available from: <https://cdss.ca/awareness/down-syndrome-answers/>

Down Syndrome FAQs. Available from:

<https://www.childrencolorado.org/doctors-and-departments/departments/down-syndrome/resources/down-syndrome-faqs/>

Frequently Asked Questions. Down Syndrome Resource Foundation. Available from: <https://www.dsrf.org/faq/>

Relationships & Sexuality | National Down Syndrome Society (NDSS) [Internet]. Available from: <https://ndss.org/resources/relationships-sexuality>

RESOURCES AND BIBLIOGRAPHY

ORGANISMS AND RESOURCES AVAILABLE

NON-PROFIT ORGANIZATIONS

NOM	DESCRIPTION	TÉLÉPHONE	COURRIEL
Asso. de Sherbrooke pour la déficience intellectuelle	Association whose objective is to promote the well-being, the social inclusion, and the rights of people with intellectual deficiencies.	819 436-2227	info@asdiorg.qc.ca
Asso. des personnes handicapées de la MRC de Coaticook	Association which defends and promotes the interests of people with handicaps.	819 849-4949	info@aphcoaticook.ca
Asso. sportive des jeunes handicapés de l'Estrie	Association that promotes sporting activities in young people with handicaps in order to positively influence their wellbeing and mental health.	819 849-0351	direction@asjhe.com
Autisme Estrie	Organism which offers services to families living with children diagnosed autism spectrum disorder in order to promote harmonious family life at home.	819 822-3918	intervenantcommunautaire@autismeestrie.com
Best buddies	Best Buddies builds friendships between neurodivergent and neurotypical people, aiming to increase social inclusion among people living with intellectual deficiencies.	888 779-0061	info@bestbuddies.ca
Han-Droits	Non-profit organization which aims to defend the rights of people living with handicaps in the MRC of Memphrémagogue.	819 868-0299	handroit@cgocable.ca
Les étincelles du Bonheur du Haut-Saint-François	Non-profit organization which aims to improve the quality of life, and promote social inclusion of people living with handicaps in the MRF of Haut Saint-François.	819 832-3540	info@etincelleshst.ca
Les Fantastiques de Magog	Organism which offers a day camp aiming to improve the quality of life and the living conditions of people with intellectual deficiencies. The day camp includes a multitude of varied activities, which in turn maintains social skills and inclusion.	819 847-2477	info.fantastiquedemagog@gmail.com
La Maison Caméléon	Organism which offers a respite for families living with people with handicaps.	819 562-6881	maisoncameleon@videotron.ca
Les Soupapes de la Bonne humeur	Organization with a mission to improve the living conditions of people with disabilities and their families, regardless of age and type of disability in the Granit MRC.	819 583-1655	info@soupapesdela-bonnehumeur.com

OTHER RESOURCES

NOM	DESCRIPTION	TÉLÉPHONE	COURRIEL
Action Handicap Estrie	Regional grouping of 19 organizations promoting the interests and defending the rights of people with disabilities in the Estrie region.	819 821-4245	ahe1986@hotmail.com
Asso. québécoise pour le loisir des personnes handicapées	Organization acting as a leader in providing accessible, inclusive, and high-quality leisure experiences, along with safe practices that enable the mobilization of the potential of people with disabilities and foster enriching and reciprocal social interactions.	819 693-3339	info@aqlph.qc.ca
Alliance québécoise des regroupements régionaux pour l'intégration des personnes handicapées	Organization formed by 17 regional associations with the main mission to promote the interests and defend the rights of people with disabilities and their families. It aims for the social inclusion of these individuals and their full participation in our society.	418 694-0736	aqriph@videotron.ca
Curateur public du Québec	The Public Curator ensures the protection of incapacitated persons and the assets of minors. It raises awareness in the population about incapacity and the importance of taking action before it occurs.	819 820-3339	—
Société Québécoise de la déficience intellectuelle	The SQDI brings together, informs, and equips all those who wish to make Quebec a more inclusive society, where everyone can find their place and flourish.	514 725-7245	info@sqdi.ca
Office des personnes handicapées du Québec	Governmental organization that contributes to increasing the social participation of people with disabilities.	1 800 567-1465	info@ophq.gouv.qc.ca

SCHOOL-RELATED RESOURCES

NOM	DESCRIPTION	TÉLÉPHONE
Commission scolaire des Hauts-Cantons	Coaticook : Primary school Gendreau et Secondary school La Frontalière East Angus : École du Parchemin et Secondary school Louis-Saint-Laurent Lac-Mégantic : Primary school Notre-Dame- de-Fatima et Polyvalente Montignac Weedon : École primaire Sacré-Cœur	819 832-4951
Commission scolaire de la région de Sherbrooke	Primary-secondary school du Touret École Sainte-Anne Secondary school du Triolet	819 822-5540
Commission scolaire des Sommets	Magog : Primary school Brassard-Saint-Patrice, Secondary school de la Ruche Saint-François-Xavier-de-Brompton : Primary school de l'Arc-en-Ciel Asbestos : Primary school de la Tourelle, Secondary school de l'Escale Windsor : Secondary school le Tournesol	819 847-1610
Guide pour soutenir la démarche de transition de l'école vers la vie active (TEVA)	The transition from school to active life is a planned, coordinated, and concerted process of activities aimed at supporting the young person in the development and realization of their life project. This process also aims to support them during their transition from school to active life.	1 866 747-6626
Programme déficience intellectuelle et trouble du spectre de l'autisme (CRDI-TSA)	Development of social skills and assessment of growth situations to support the individual by reducing their disabilities, promoting autonomy, improving their quality of life, and ensuring social integration.	819 346-8471

CIUSSS BY MUNICIPALITY / REGION

To find the integrated university center closest to you, please consult the following list:

https://www.santeestrie.qc.ca/clients/SanteEstrée/A_propos/Installations_CIUSSS-CHUS_Intra-net_dec2022.pdf

SOURCES

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See above for available organizations.

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Agence du revenu du Canada. Qu'est-ce qu'un régime enregistré d'épargne-invalidité (REEI) [Internet]. 2007 [cité 23 févr 2024].

Disponible à: <https://www.canada.ca/fr/agence-revenu/services/impot/particuliers/sujets/regime-enregistre-epargne-invalidite-reei.html>

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F.A.Q

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Available from: <https://www.dsrf.org/faq/>

Relationships & Sexuality | National Down Syndrome Society (NDSS) [Internet].
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RESOURCES AND ORGANIZATIONS AVAILABLE

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Available from: <https://www.asdet21.org/>

The available organizations are in the indicated section.

ANNEX

GROWTH CHARTS – GIRLS 0 À 36 MONTHS

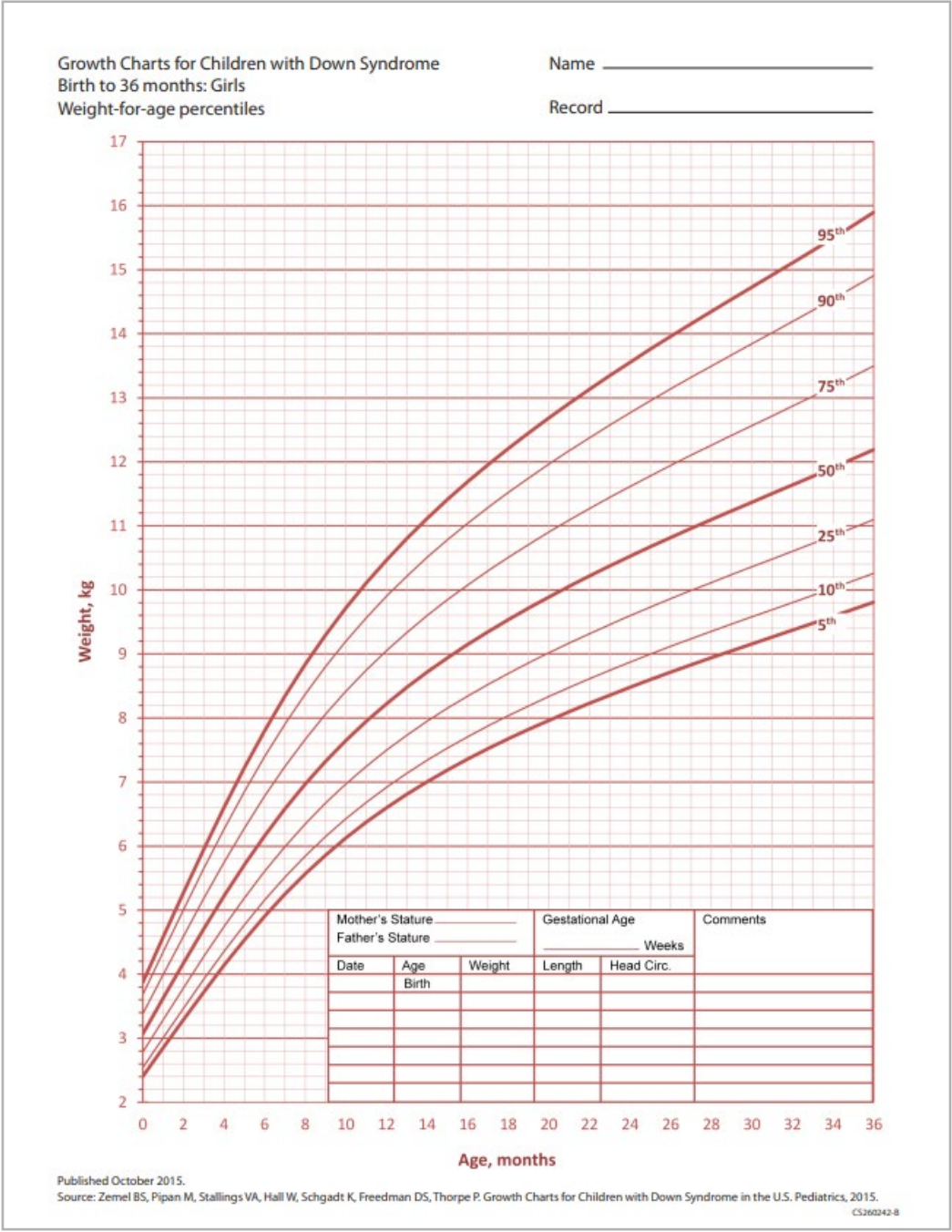


Figure 2 : Weight (kg) in relation to age (months)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome | CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – GIRLS 0 À 36 MONTHS

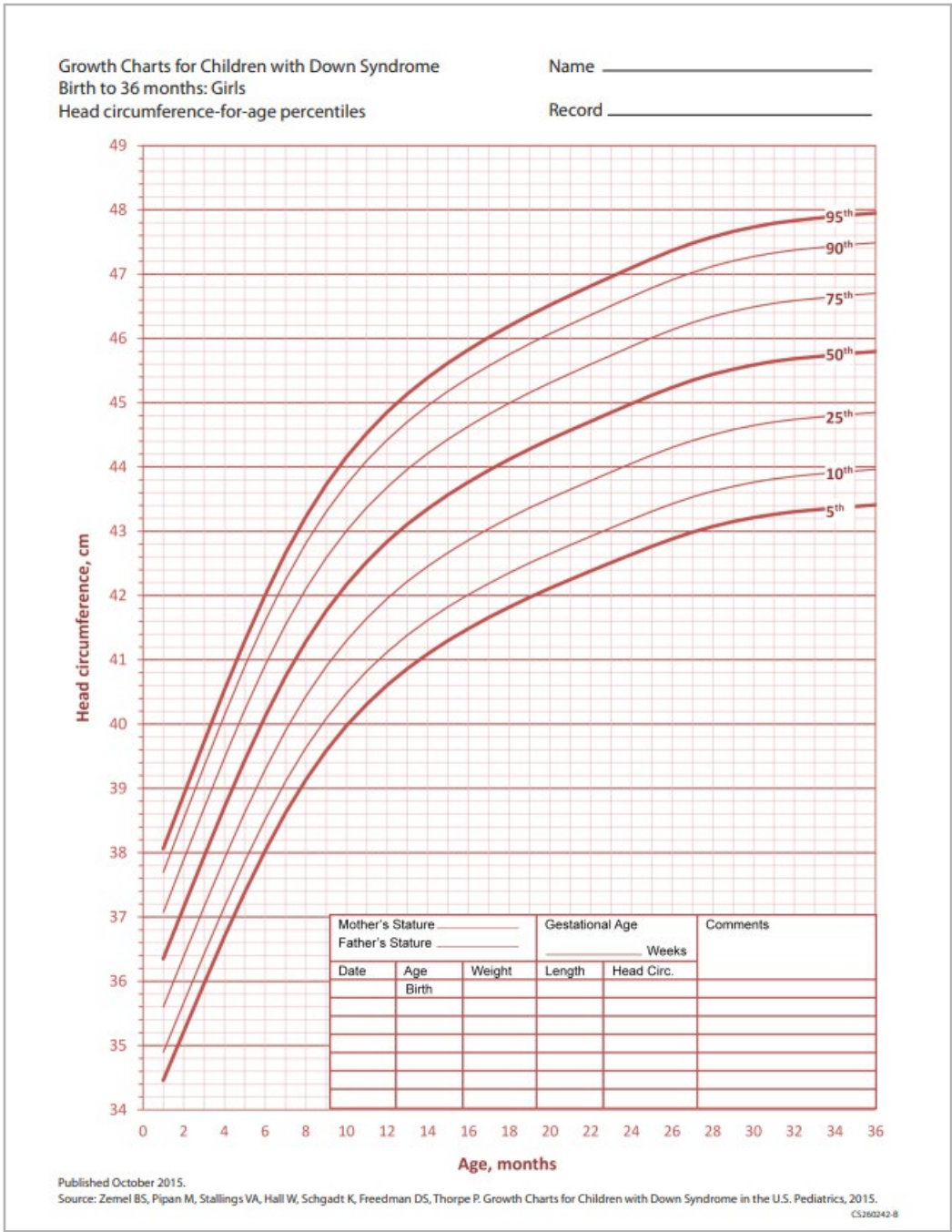


Figure 3 : Height (cm) in relation to age (months)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome |
CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – GIRLS 0 À 36 MONTHS

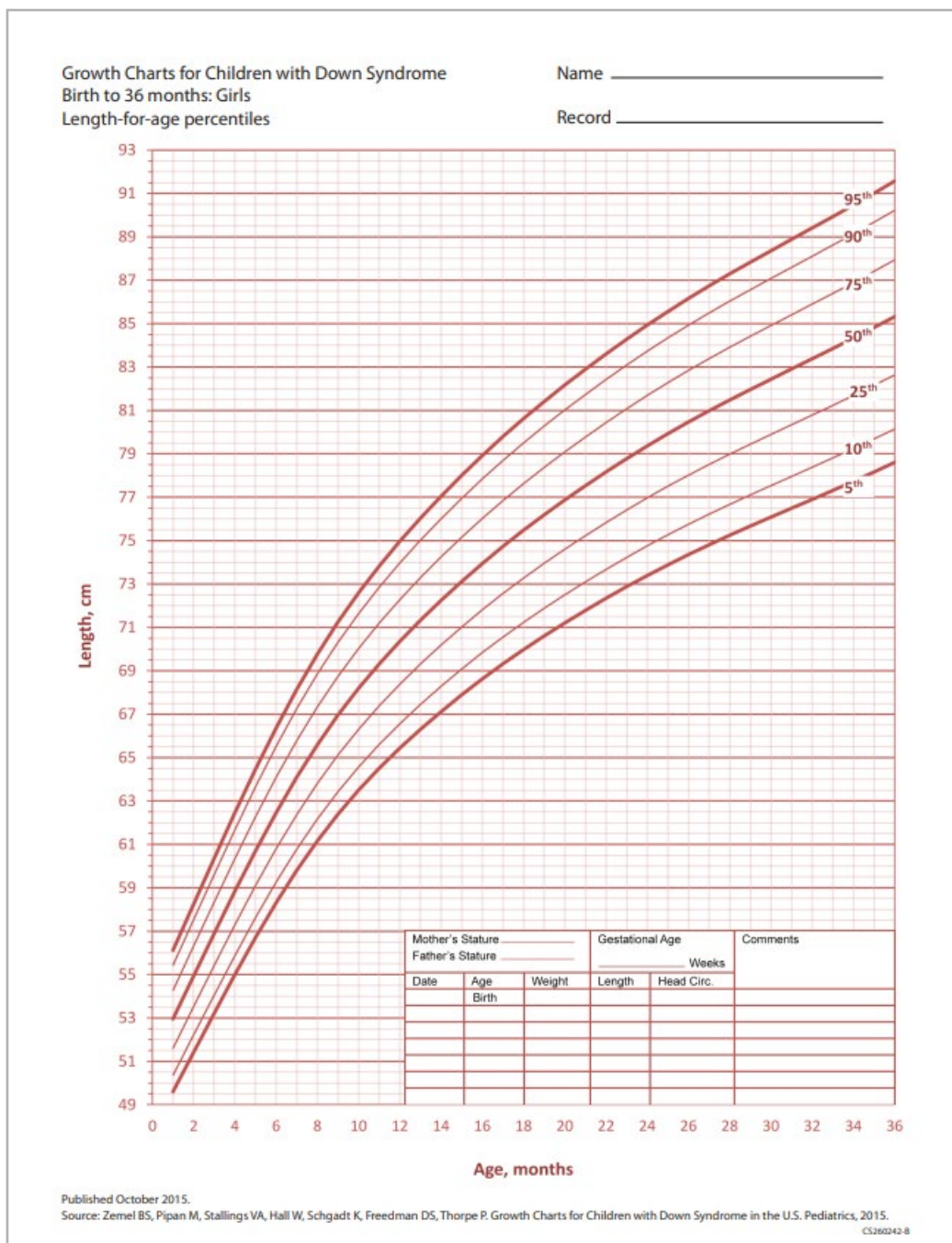
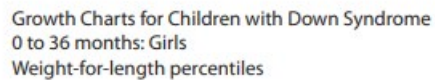


Figure 4 : Cranial circumference (cm) in relation to age (months)

SOURCES

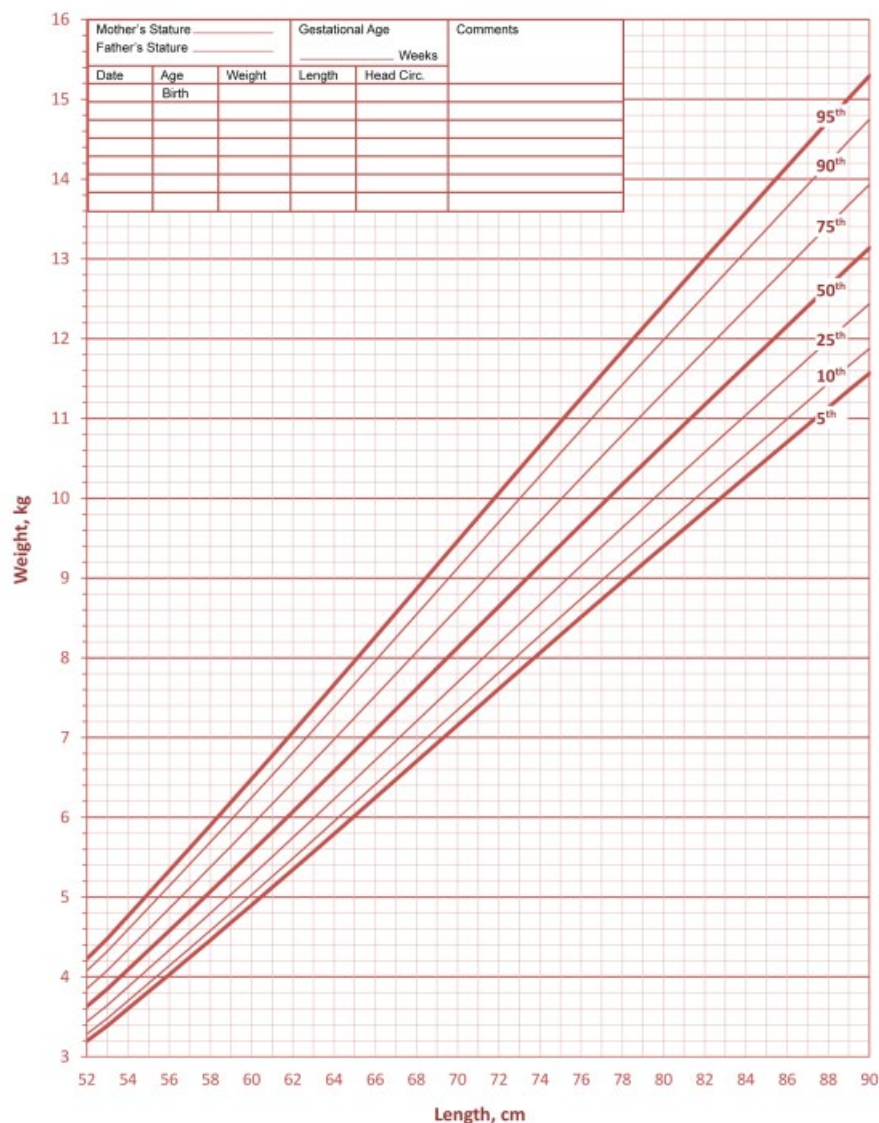
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GROWTH CHARTS – GIRLS 0 À 36 MONTHS



Name _____

Record _____



Published October 2015.

Source: Zemel BS, Pipan M, Stallings VA, Hall W, Schgadt K, Freedman DS, Thorpe P. Growth Charts for Children with Down Syndrome in the U.S. *Pediatrics*, 2015.

CS260242-8

Figure 5 : Weight (kg) in relation to height (cm)

SOURCES

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CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – BOYS 0 À 36 MONTHS

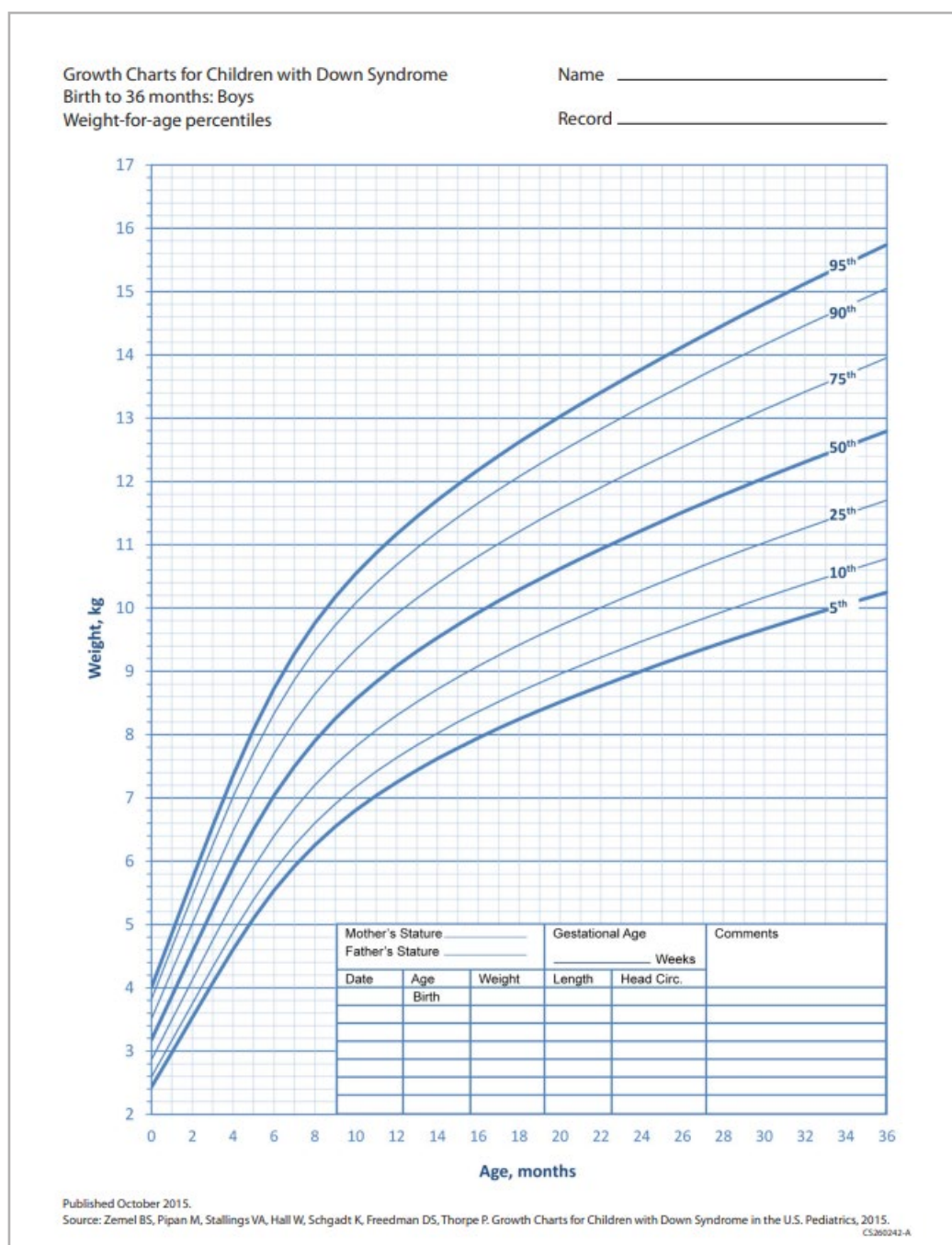


Figure 6 : Weight (kg) in relation to age (months)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome |
CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – BOYS 0 À 36 MONTHS

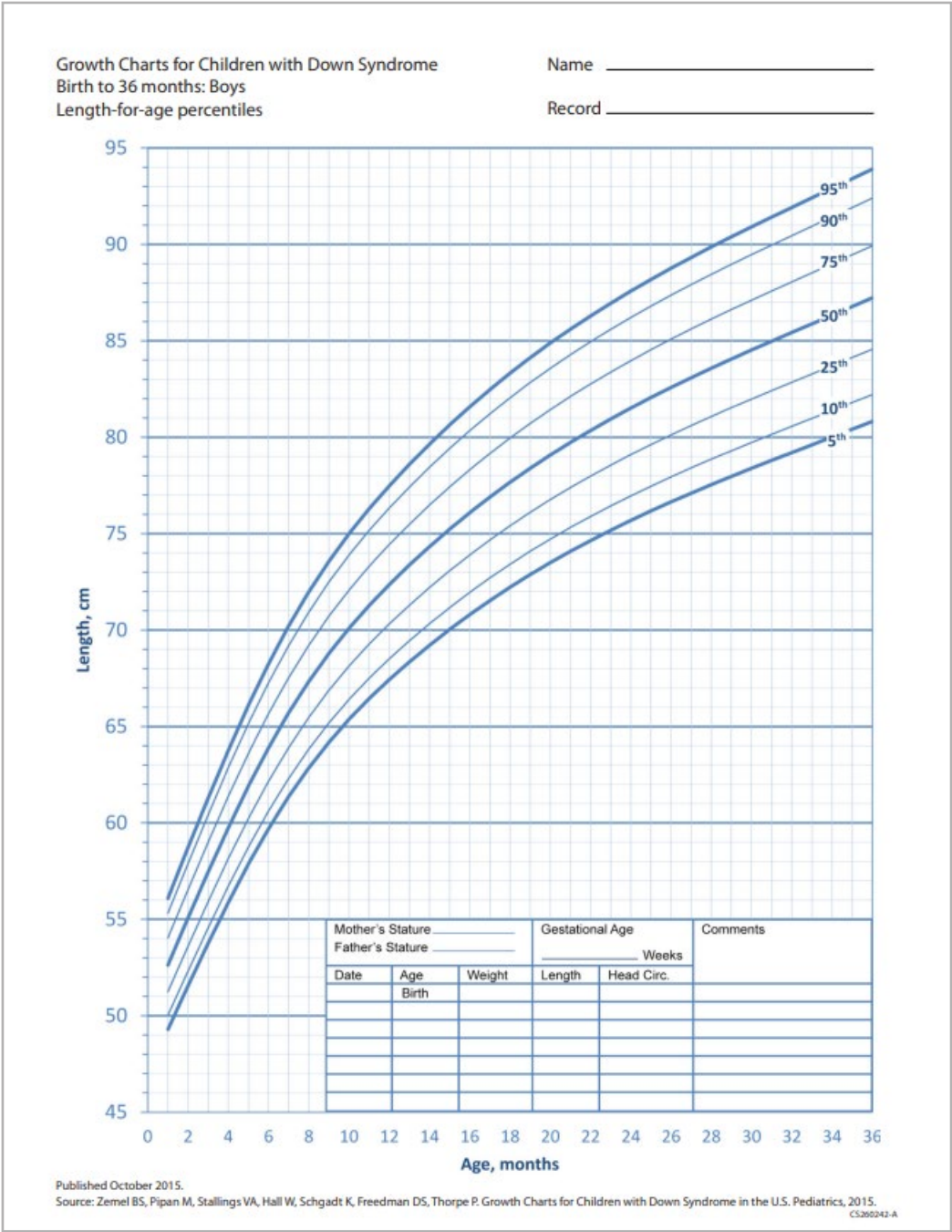


Figure 7 : Height (cm) in relation to age (months)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome |
CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – BOYS 0 À 36 MONTHS

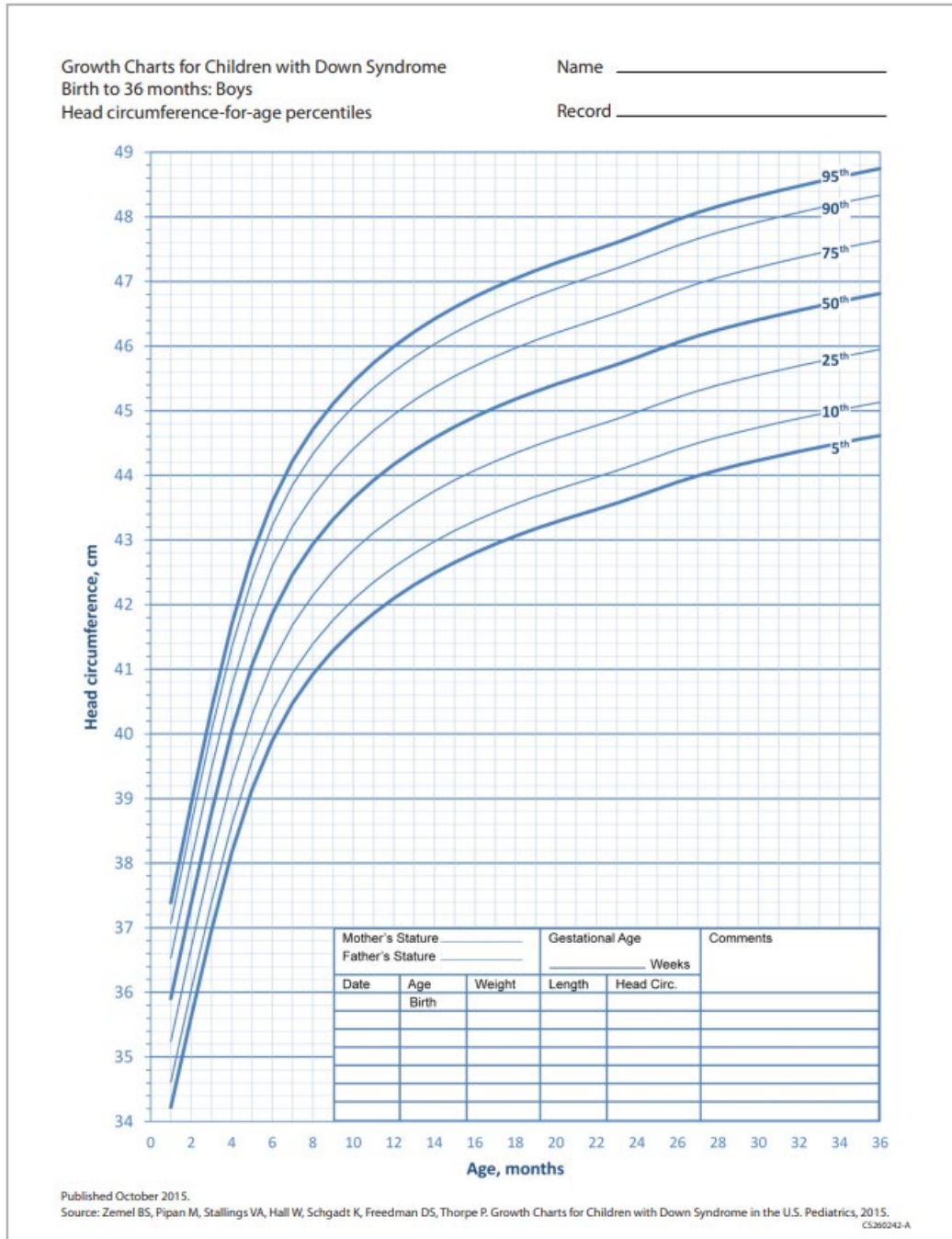


Figure 8 : Cranial circumference (cm) in relation to age (months)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome | CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – BOYS 0 À 36 MONTHS

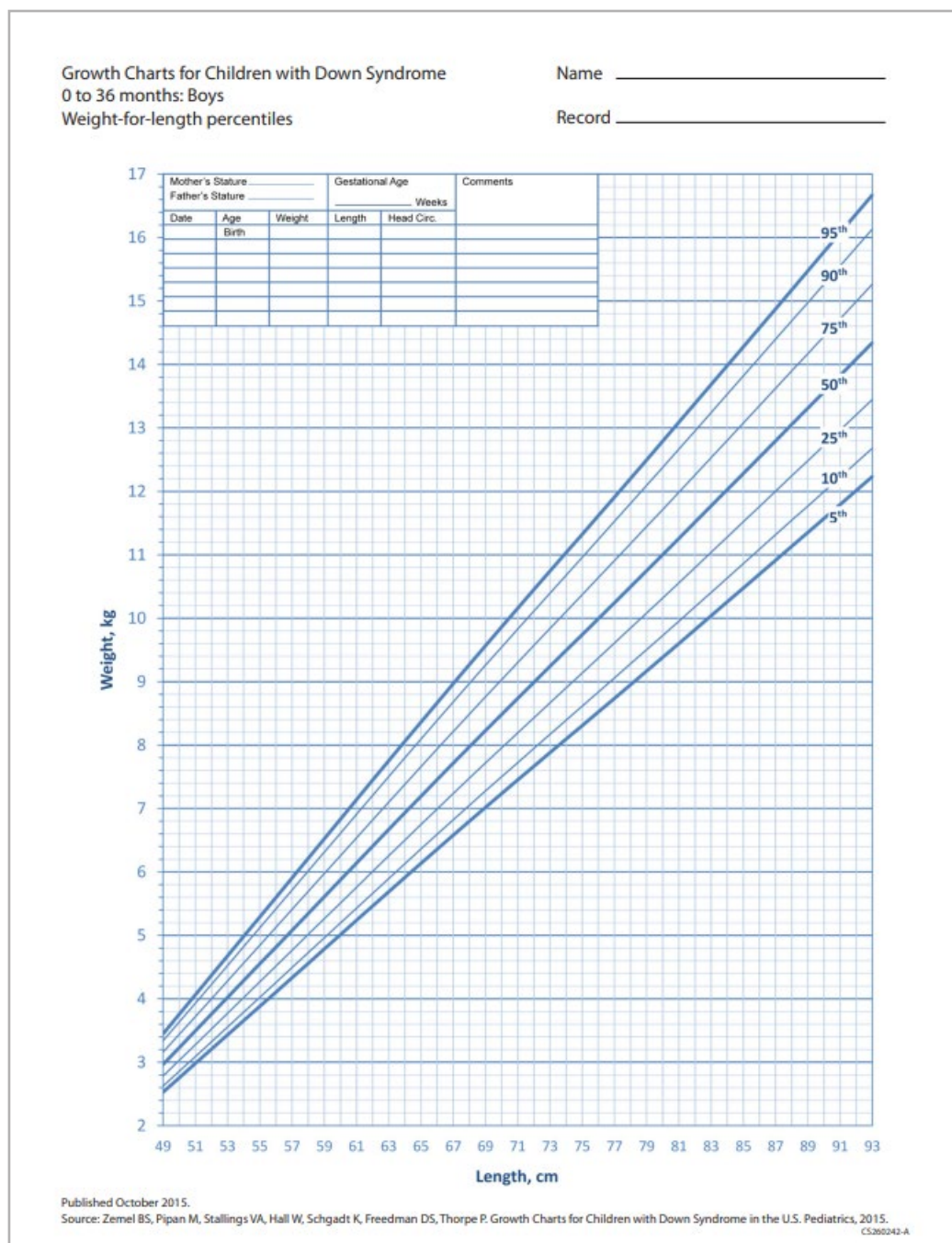


Figure 9 : Weight (kg) in relation to height (cm)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome | CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – FILLES 2 - 20 YEARS OLD

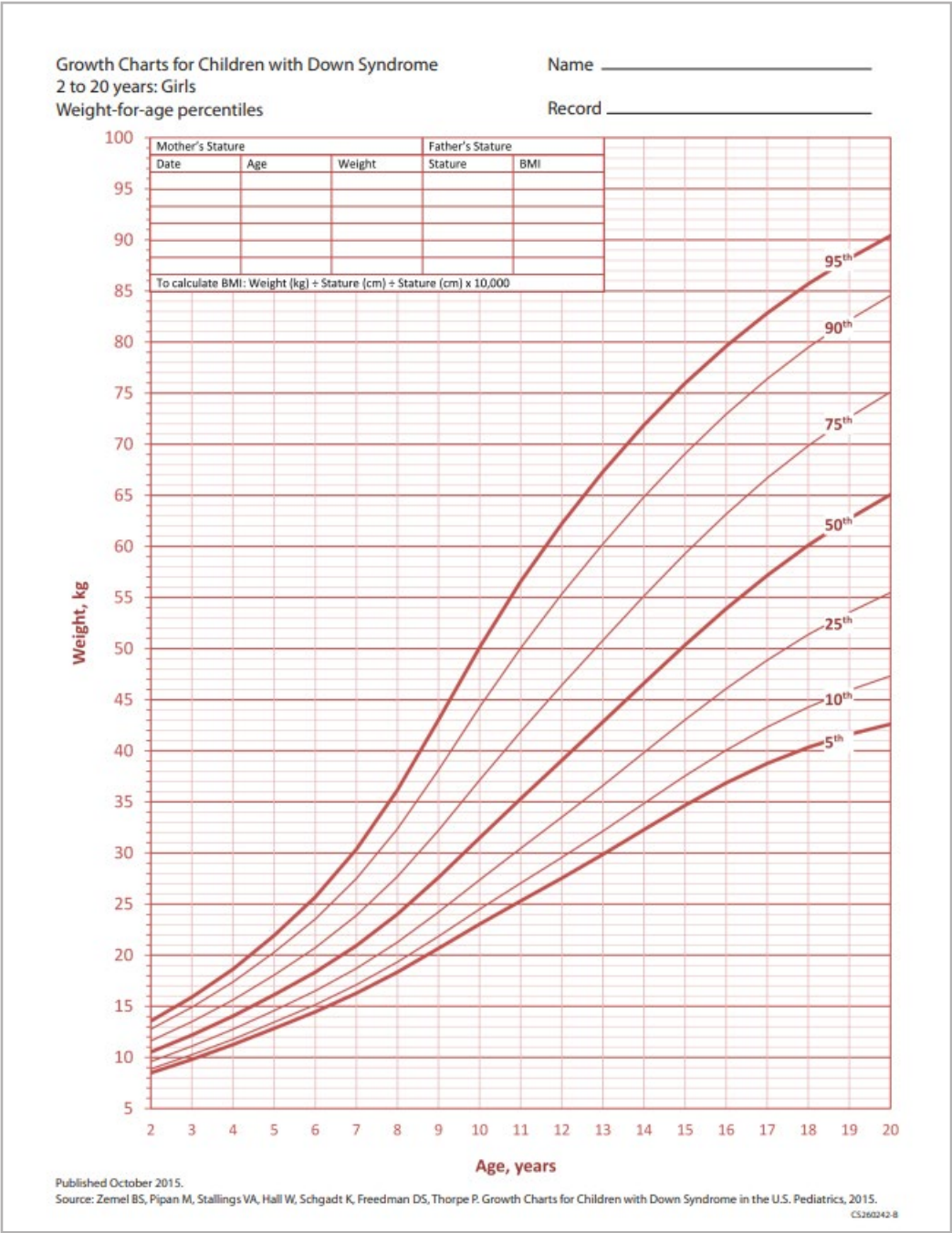


Figure 10 : Weight (kg) in relation to age (years)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome |
CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – FILLES 2 - 20 YEARS OLD

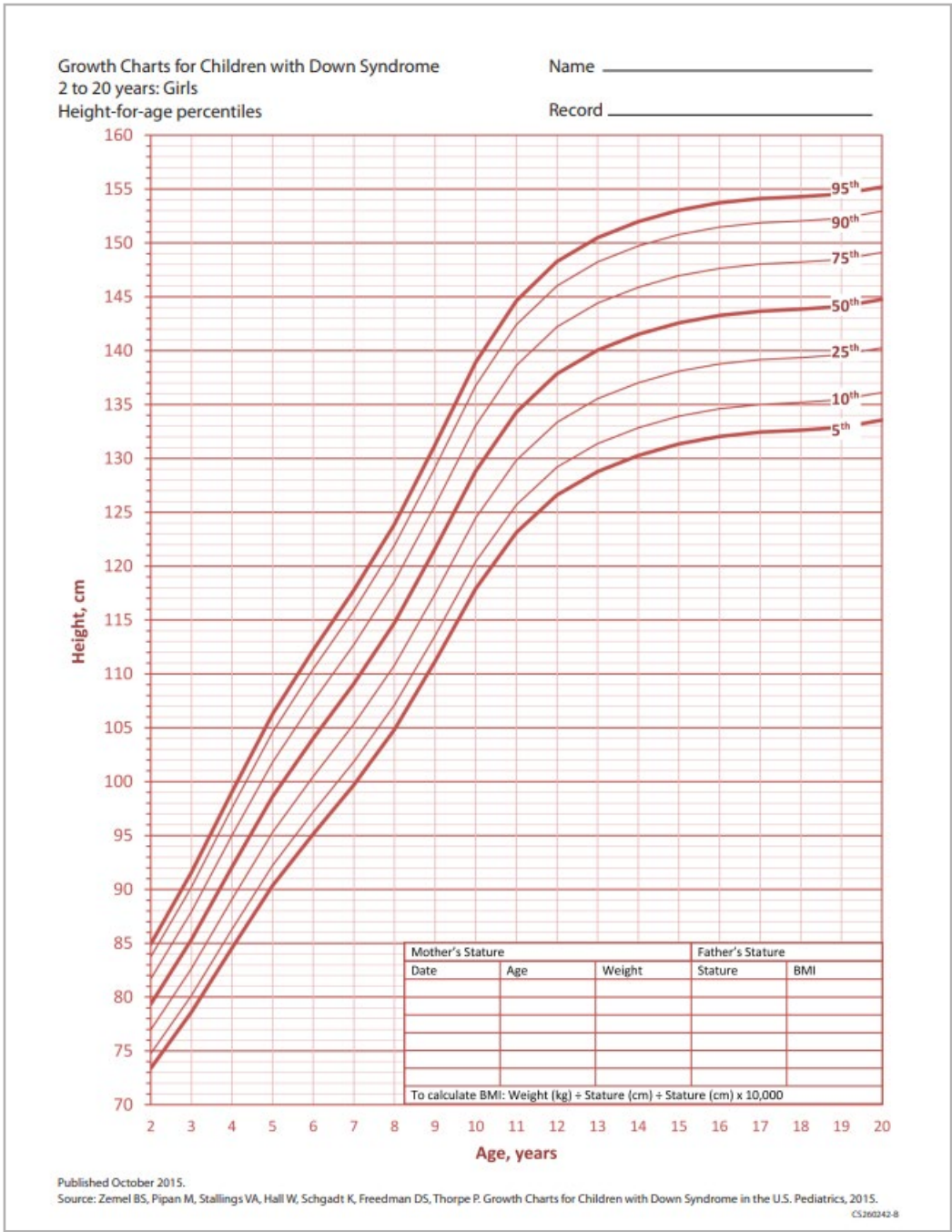


Figure 11 : Height (cm) in relation to age (years)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome |
CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – FILLES 2 - 20 YEARS OLD

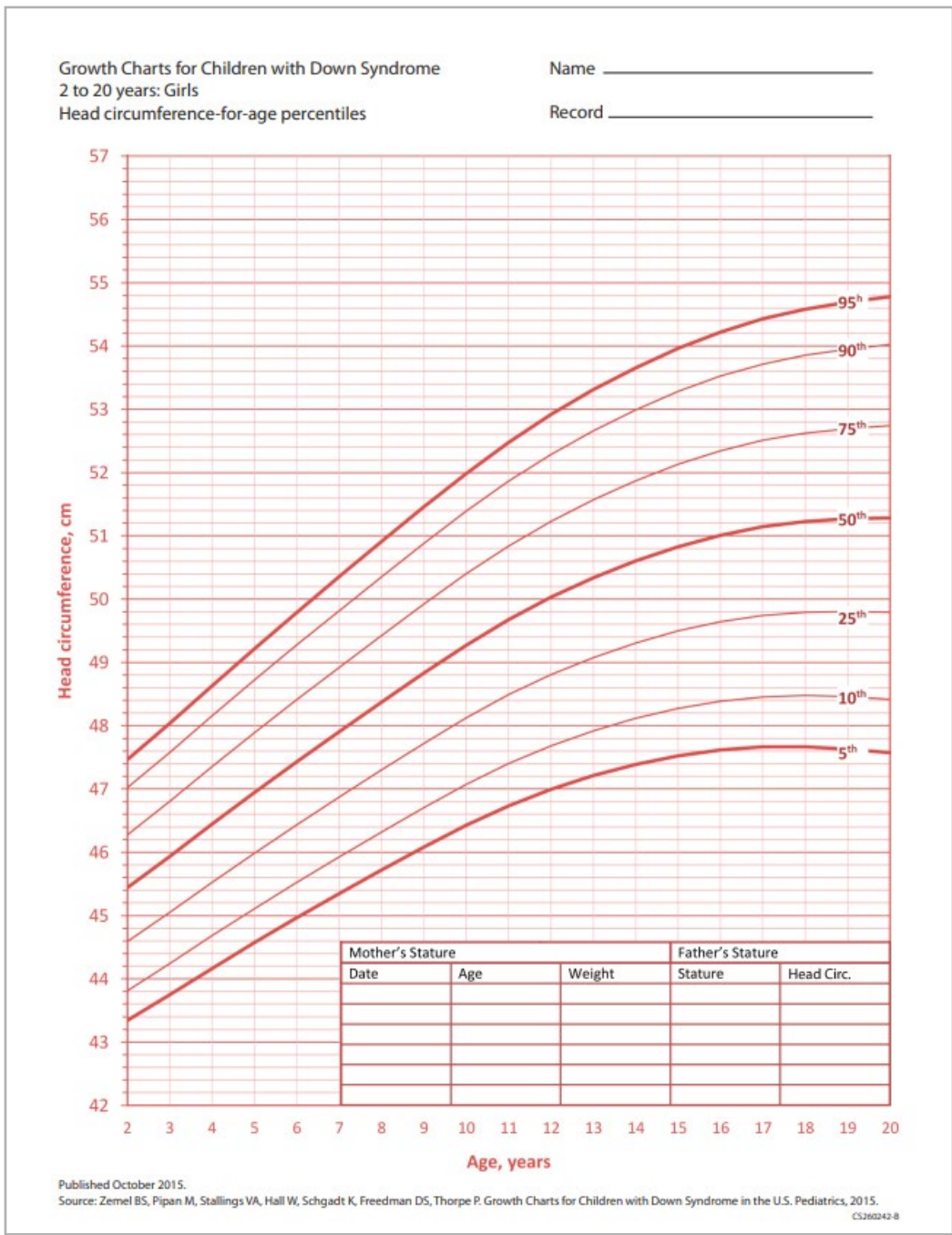


Figure 12 : Cranial circumference cm) in relation to age (years)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome |
CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – BOYS 2 - 20 YEARS OLD

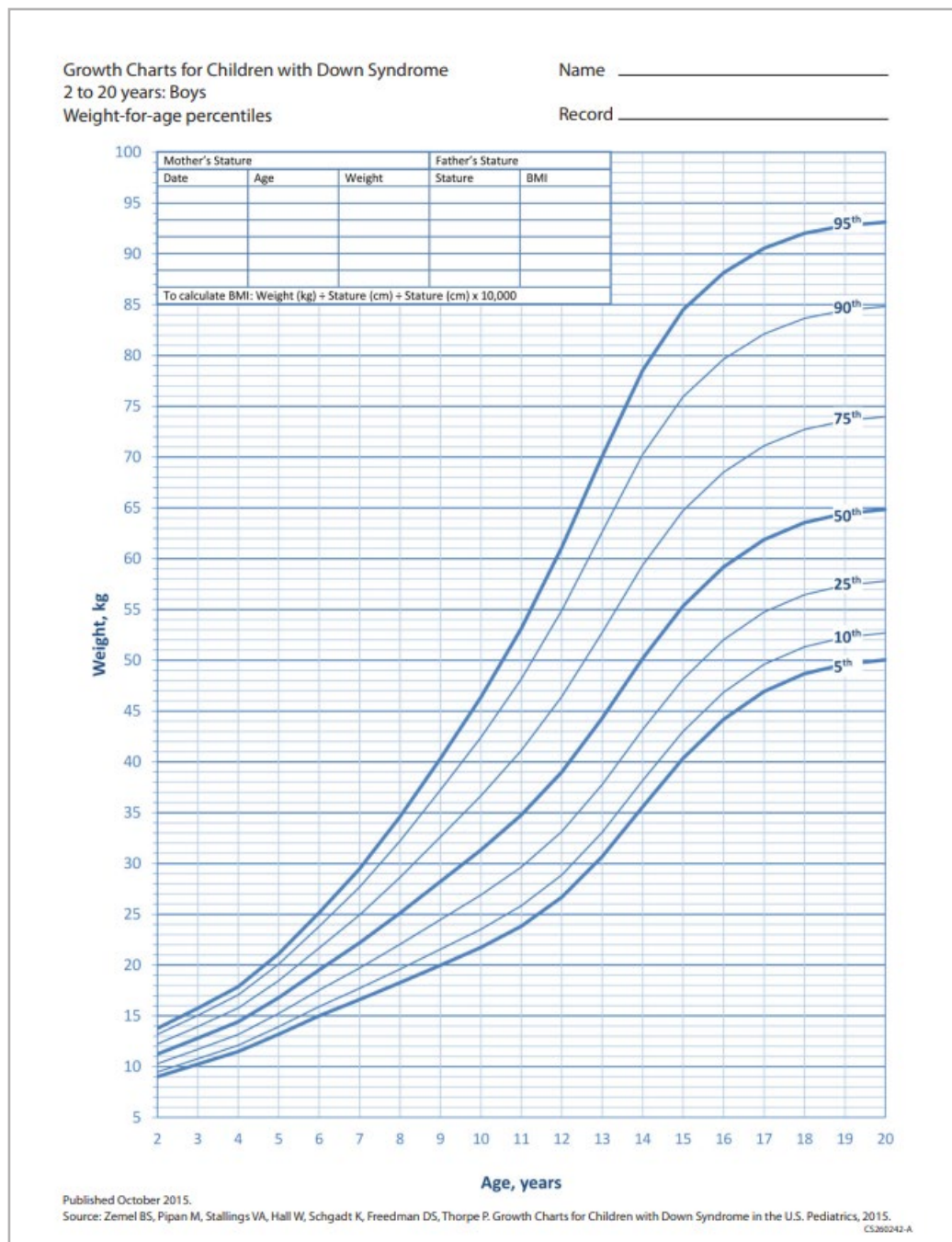


Figure 13 : Weight (kg) in relation to age (months)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome | CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – BOYS 2 - 20 YEARS OLD

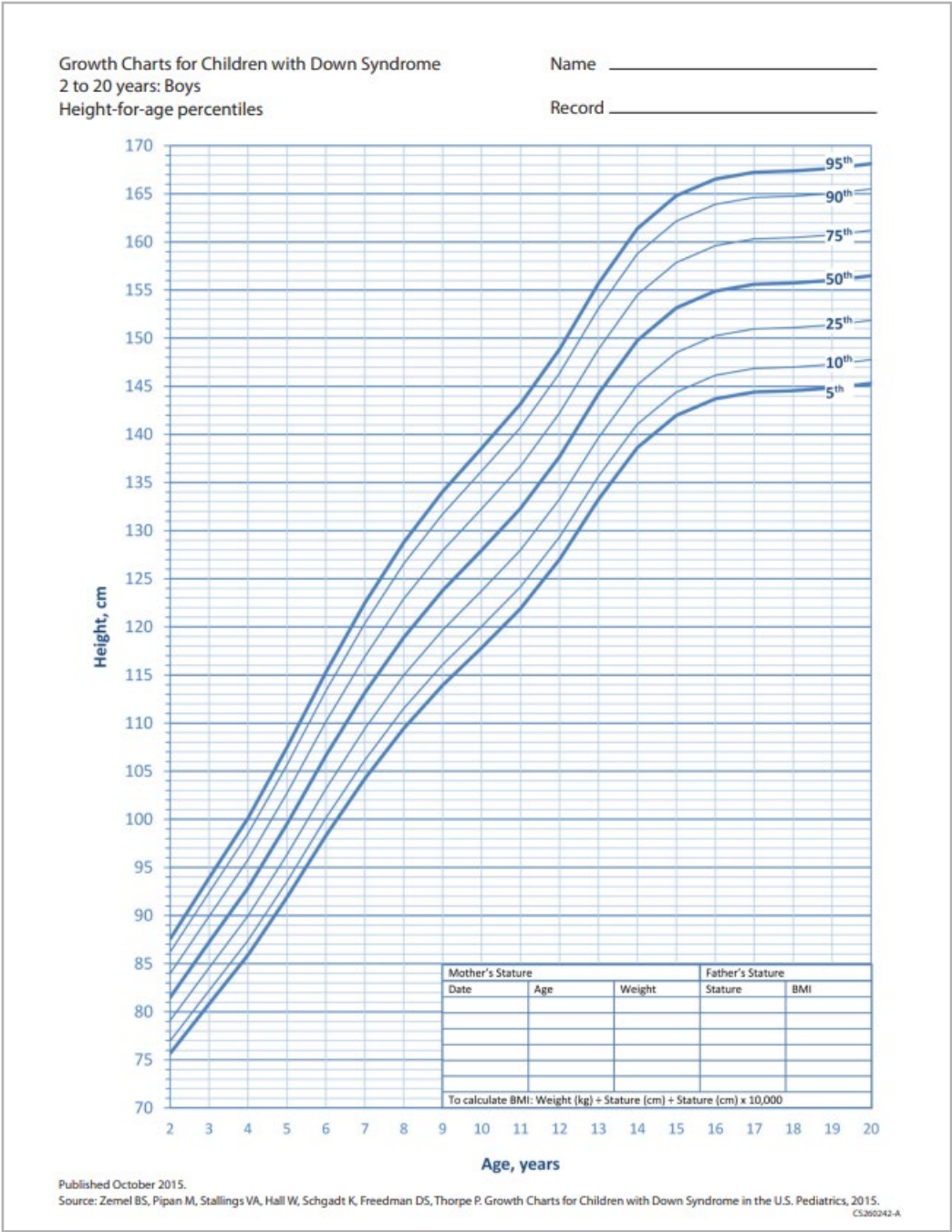


Figure 14 : Height (cm) in relation to age (years)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome | CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

GROWTH CHARTS – BOYS 2 - 20 YEARS OLD

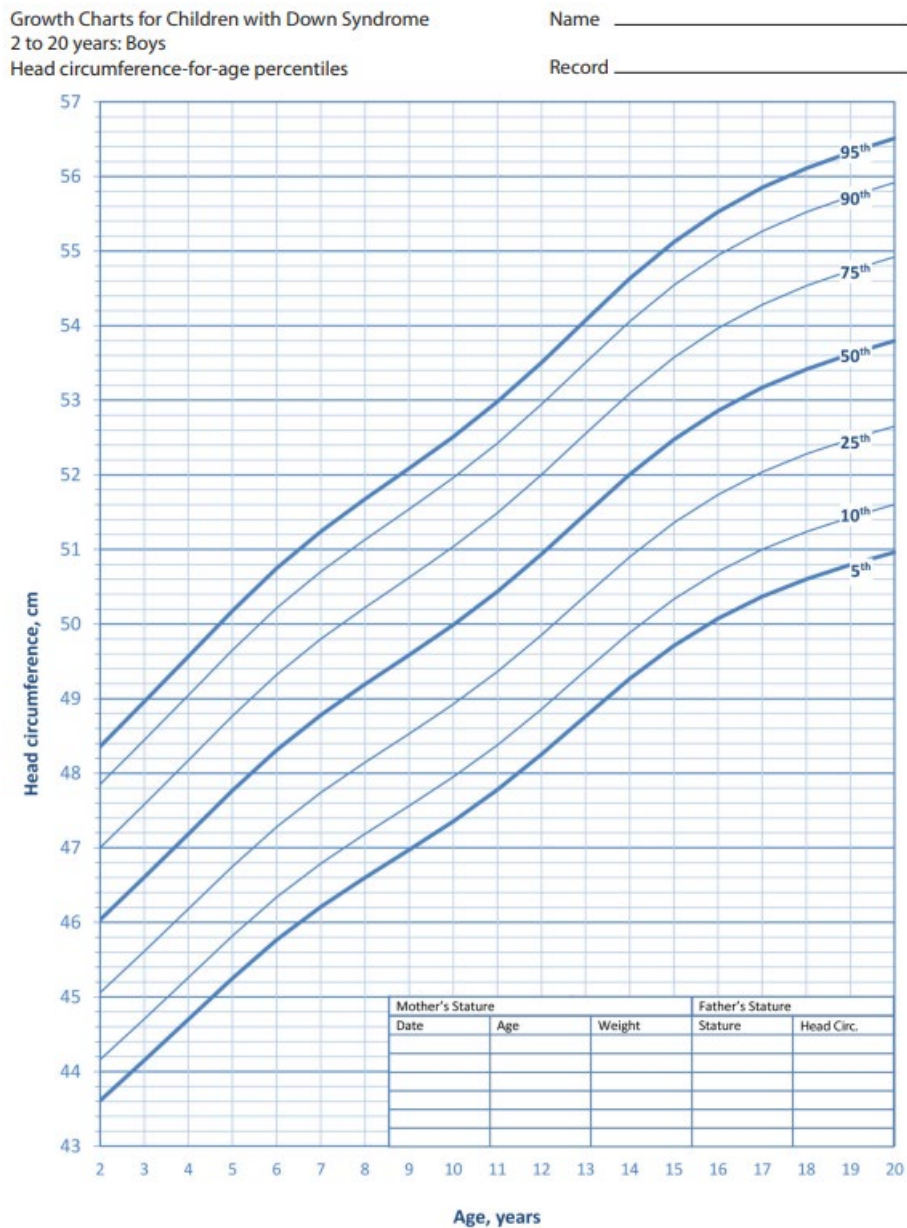


Figure 15 : Cranial circumference (cm) in relation to age (years)

SOURCES

CDC. Centers for Disease Control and Prevention. 2023. Growth Charts for Children with Down Syndrome | CDC. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html>

