

# Trisomy 18

## Maternal and Child Health Handbook



Name

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Day of birth

Day

Month

Year

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Please put a picture of your child or family here.



My contact information



## Trisomy 18 Maternal and Child Health Handbook

A handbook for children with trisomy 18 and their families.

It can be filled out and used for the period from pregnancy to age 6.

We also made a special effort to have the hospital staff and home support staff write messages to us.

We hope that everyone involved, especially children with trisomy 18, will make this handbook a valuable resource for them.



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A little treasure

Your being here

You may be overwhelmed by what you have heard from your doctor or by the information you gathered from the Internet.

Although appropriate information is of course necessary, remember to take some time to feel and engage with the life you are carrying and temporarily set aside the facts and figures (and the anxiety they may bring).

Your baby will send you various messages, like "I am here," "I'm alive," or "I'm trying to live."

Value how you feel at any moment. Embrace the various emotions you experience – try not to deny even feelings of doubt or fear. Having a variety of emotions is perfectly normal, and every feeling or struggle is valid.

Such experiences will actually help you and empower you to meet your baby as parents.

Share your feelings with someone who will be there for you in times of difficulty.

## Things to keep in mind during pregnancy



If you are pregnant and your child has been diagnosed with trisomy 18, you may be concerned about the child's development and what will happen after the child is born. You may also be concerned about how you will spend your pregnancy.

It is recommended that you first consult with your obstetrician and gynecologist, and have an early opportunity to talk with the pediatrician (neonatologist) who will be treating your child after birth.

More and more medical institutions are offering meetings between the parents and the pediatrician, and clinical psychologists are joining the meetings to support the family.



## Things to keep in mind during pregnancy



The way the mother spends her pregnancy does not change particularly because her child has trisomy 18. However, depending on the child's complications, more amniotic fluid may be produced, causing signs of preterm labor.

It is important to have a proper prenatal checkup because it (Trisomy 18) may cause problems with your child's heart rate and growth.

If you have symptoms such as an upset stomach or bleeding, contact your health care provider as soon as possible to get the necessary medical attention.

This is common to all pregnant women, but daily blood pressure monitoring at home is recommended as it can lead to early detection of hypertensive disorders of pregnancy.

This is the time when you can feel the movement of the baby and the daily movement is a sign that the baby is healthy.

It is natural to feel uneasy when looking at the ultrasound images and what the doctor has explained to you.

This anxious feeling can be relieved when you meet your baby.

It is also a good idea to talk with mothers who have actually given birth to a child with trisomy 18 during pregnancy through the Trisomy 18 Support Group.





MEMO

A little treasure

Your birth

Congratulations on the birth of your baby!

Your baby is here to meet you. Your baby is lucky to have you as a mother and a father.

Although medical procedures are essential to save your baby's life, ask the medical staff to help you connect with your baby by looking at them, touching them, and smelling them.

We hope you have time to get to know your baby, acknowledging, "You are the one I was carrying," and to introduce yourself to your baby by telling them, "I'm your mom/dad."

Even if it is just a short introduction, it will be a precious moment marking the beginning of your baby's life and the start of your new family history.

However, this moment together does not have to be right after birth if the situation does not allow. In this case, still cherish the moment, and your thoughts of "Thank you for coming into our lives" will be conveyed.

## Record of the time of birth

Birthdate

( Day/ Month/ Year)

Expected delivery date

( Day/ Month/ Year)

embryonic period

( Week)

Birth weight	g
Height	cm
Head size	cm
Chest size	cm



# Message from Parents



A series of 15 horizontal dotted lines for writing.



# Messages from Hospital Staff



A series of horizontal dotted lines for writing messages.



MEMO

A little treasure

Your heart feeling the wind,  
the sunlight,  
the air

You may be overwhelmed by seeing your baby connected to monitors or machines in the NICU. This may even make you feel hesitant to touch your baby. However, the machines are there to help your baby, and your presence and touch can be just as beneficial.

As you spend more time with your baby, you will notice how they see the world and try to communicate with you by moving their little legs and hands, looking at you, and smiling at you.

Even though your baby needs to be cared for by medical staff, you are your baby's family. The bond between you and your baby will be fostered and nurtured even in the NICU.

The medical team aims to provide you and your baby with a comfortable environment throughout your baby's time in the hospital. Let the medical staff know if you have some ideas for your baby's care. The medical team is more than happy to work together with you to make your plan possible for your baby.



Memorial  
handprints

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Day/

Month/

Year)

Date taken



Memorial  
footprints

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Day/

Month/

Year)

Date taken

# Medical Information



One complication that requires treatment is that most children with trisomy 18 (syndrome) have congenital heart disease. Some types are more frequent and have increased pulmonary blood flow, such as ventricular septal defect, atrial septal defect, and patent ductus arteriosus, while others are less frequent and more complex, such as tetralogy of Fallot and double-outlet right ventricle. In the type of congenital heart disease that increases pulmonary blood flow, pulmonary hypertension tends to be more severe in early infancy. Respiratory complications may include diaphragmatic relaxation, airway obstruction, and apnea.

Gastrointestinal complications include esophageal atresia, omphalocele, and imperforate, which may warrant early postnatal surgery. Gastroesophageal reflux is a complication that becomes apparent some time after birth and poses problems in respiratory, nutritional, and infection control.

Urinary complications include horseshoe kidney, hydronephrosis, and inguinal hernia.

Skeletal complications may include articular contracture and scoliosis.

Ophthalmologic complications such as ametropia and photosthesia (glare) may also occur.

Development is generally slow, including motor, comprehension, and language skills.

# Medical Information



Aggressive medical treatment (neonatal intensive care such as respiration management, surgery for cardiac problems, surgery for gastrointestinal problems, treatment of convulsion, and rehabilitative support) has been shown to improve both life expectancy and quality of life. Your child will continue to develop slowly but steadily. The family sees the child's presence as a positive thing and knows that the child will respond to it. The medical staff and the family share information about the disease and the child's physical condition to provide the best medical and educational support for the child. In addition, psychosocial support for the family is also important.



## Vaccine

A study conducted by SOFT showed that there were no specific side reaction to vaccinations that are commonly given. In Japan as well, vaccinations can be given as usual while monitoring the child's condition. In addition, prophylactic administration of Synagis is recommended because RS virus infection can be severe. In addition, because of the high prevalence of cardiac and respiratory complications, the COVID-19 vaccination is expected to be a priority. We recommend that you discuss this with your doctor and consider it positively.

# Health care starting from NICU 1



## 🌀 Perinatal care

In case of prenatal diagnosis or suspicion, a pre-natal visit (greeting by the pediatrician [neonatologist] and nursing staff who will be treating the child) is conducted. After birth, appropriate resuscitation will be performed depending on the child's condition (e.g., endotracheal intubation).

## 🌀 Basic measures for the neonatal period

Provide respiratory support (including oxygen administration and artificial ventilation) according to the child's condition.

Nutrition, temperature, infection, jaundice, etc. will be administered. Tube feeding (gastric tube) will be done in most cases.

Chromosome examination is performed to confirm the diagnosis. Based on the most up-to-date and comprehensive information from the natural history and health history, the best medical treatment and support for the child should be found.

## 🌀 Respiratory complications

Early detection of apneic attacks and hypoxemia by monitoring oxygen saturation (SpO<sub>2</sub>) and respiratory heart rate.

If the child's respiratory status is unstable (some problems are in the upper respiratory tract, while others are in the lower respiratory tract such as lungs or bronchi), or if there are respiratory infections or recurrent atelectasis, the cause is investigated by X-ray or CT. Treatment includes respiratory support using oxygen administration and artificial ventilation, and drug therapy using antibiotics and expectorants.

If apneic attacks occur, a search for the cause (which may be a symptom of convulsions) will be conducted and optimal treatment will be given.

## 🌀 Cardiovascular complications

Early after birth, X-ray and ultrasonography are performed. It should be accurately diagnosed whether the children has congenital heart disease, and if so, what type and severity of the disease. In the case of diseases that increase pulmonary blood flow (ventricular septal defect, patent ductus arteriosus, etc.), we pay attention to the progression of heart failure and pulmonary hypertension, and provide the best medical treatment (fluid restriction, diuretics, inotropic drugs, etc.) according to the child's condition. Based on the evidence of surgery for congenital heart disease, we will consider the indications for surgery based on the child's circulatory dynamics and general condition. The family, pediatricians (neonatologists), pediatric cardiologists, cardiac surgeons, and nursing staff will discuss the best treatment for the child's health condition.

# Health care starting from NICU 2

## 🌀 Digestive complications (including nutrition and feeding)

Pediatric surgeons are available to treat suspected gastrointestinal complications such as congenital esophageal atresia and imperforate that require treatment early after birth. Based on an accurate diagnosis, the best treatment (including surgery) will be given according to the child's condition. Oral intake training will be provided based on accurate assessment by rehabilitation therapists while paying attention to respiratory and circulatory conditions. If gastroesophageal reflux disease is suspected, it is evaluated by upper gastrointestinal contrast and 24-hour pH monitoring. Considering the degree of reflux and the child's condition, the following measures will be considered: adding a thickener to the milk, using a duodenal tube, or performing a gastrostomy/jejunostomy. If tube feeding is prolonged, the creation of a gastrostomy and the use of enteral nutrition will be considered.

## 🌀 Neurological complications

If the child has convulsive seizures (or frequent apnea), the child will be evaluated by electroencephalography, and anticonvulsants will be administered.

## 🌀 Urological complications

Screening of the renal and urinary tract system by ultrasonography is performed in the newborn period. In case of repeated urinary tract infections, screening for vesicoureteral reflux by retrograde cystourethrography is performed. Prophylactic antimicrobial agents and surgery will be considered if necessary.

## 🌀 Otolaryngological complications

If there is a suspicion of laryngomalacia such as inspiratory wheezing, fiberoptic examination will be considered. Perform an audiometric test such as auditory brainstem response (ABR). If there is a hearing loss, the type of hearing loss (conductive, sensorineural, and mixed hearing loss) should be determined and the most appropriate treatment (hearing aid, etc.) should be given. If the child has chronic otitis media, medication (e.g., expectorant) or surgery (e.g., tympanostomy) will be performed.

## 🌀 Ophthalmological complications

Ophthalmologic examinations are performed in the newborn period, taking into consideration the complications (cataract, glaucoma, corneal opacity, strabismus) that may be present at birth. It is important to continue regular eye examinations in infancy, early childhood, and school age. Use of eyeglasses should be considered for myopia, hyperopia, and astigmatism. For photophobia, the use of sunglasses should be considered.

# Health care starting from NICU **3**

## 🌀 Musculoskeletal complications

If there are complications from birth (polydactyly, etc.), they will be addressed in consultation with orthopedic and plastic surgeons (conservative treatment, surgery).

Complications that are likely to occur after birth (scoliosis, hip dislocation, etc.) will be taken into consideration, and regular checkups and treatment (orthotics, etc.) will be provided by an orthopedic surgeon.

## 🌀 Screening for malignant tumors

After 6 months of age, abdominal ultrasonography and blood tests are performed every 6 months to screen for hepatoblastoma, Wilms tumor, etc.

## 🌀 Growth monitoring

Weight, height, and head circumference will be measured at each regular visit to monitor the progress of growth (normal growth chart and growth chart for children with trisomy 18 will be used).

## 🌀 Developmental support

Developmental support is provided from early infancy (physical therapy, occupational therapy, speech therapy [feeding and swallowing training, hearing support, communicative support], etc.).

## 🌀 Genetic problems

Genetic counseling by clinical geneticists and certified genetic counselors (including psychosocial support for families, recurrence rate of the next child, and information on prenatal diagnosis) is provided.

## 🌀 Peer support and psychological support

Introduce support groups, such as the "Trisomy 18 Support Group (<https://18trisomy.com/>)", "Support Organization for Trisomy 18, 13, and Related Disorders, SOFT (<https://trisomy.org/>)".

## 🌀 Social support

Social support systems (Physical Disability Certificate, Rehabilitation Certificate, Special Child Support Allowance, Welfare Allowance for Children with Disabilities, Pediatric Chronic Specified Diseases, etc.) are coordinated by specialists in the case of home medical care, including hospitals, rehabilitation centers, and medical care (considering the use of services such as home nursing, home rehabilitation, and respite hospitalization to reduce the burden on the child and family).



# Complications and tests



Ask your doctor to provide accurate information.

Disease name

Progress etc.

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## First memory while in hospital

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/ /	/ /
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# Records at Discharge



Discharge day (      Day/      Month/      Year)

Weight	g
Height	cm
Head size	cm
Chest size	cm

Other

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# At home information

Allergies

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Medicine

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Home visitation

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Visiting nursing

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Medical equipment  
manufacture

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Family pharmacy

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MEMO

A little treasure

Walking with you

## Home at Last!

Once your child goes home, they will be introduced to a new environment with varying light and temperatures. Your child may enjoy lively voices or notice an appetizing smell. When ready to start eating solids, your child may enjoy homemade food. If your child has a feeding tube, you can let them taste a little homemade food before mouth care.

All the enriched stimulation from daily surroundings will help your child to grow at their own pace.

As you and your child spend time together as a family, you will find a series of miracles in ordinary life.

Getting support from your community is essential, regardless of how much medical need your child may have.

Children grow not only in the family but also in the context of their community.

A society where children with Trisomy 18 have opportunities to participate in every aspect of life to the best of their abilities and desires will lead to a community that is friendly to everyone.



What you need to live at home



- Oxygen concentrator
- Mechanical ventilator
- Heat and humidity inhaler
- Aspirator
- Pulse oximeter
- Nebulizer
- Ambu bag
- Nasogastric tube
- Elemental Diet tube
- Gastric fistula tube
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## What you need to live at home



- Nutritional supplement \_\_\_\_\_
- Injection pump \_\_\_\_\_
- Irrigator \_\_\_\_\_
- Syringe \_\_\_\_\_
- Chlorinated water \_\_\_\_\_
- Suction catheter \_\_\_\_\_
- Monitor sensor \_\_\_\_\_
- Gauze \_\_\_\_\_
- Fixing tape \_\_\_\_\_
- Stethoscope \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



MEMO

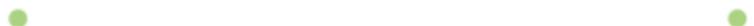
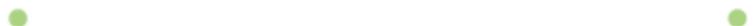
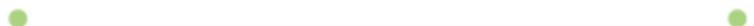
# When baby first comes home



Situation



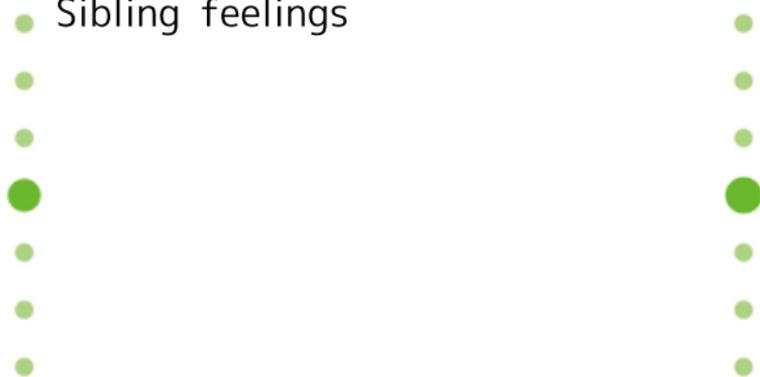
Parent's feelings



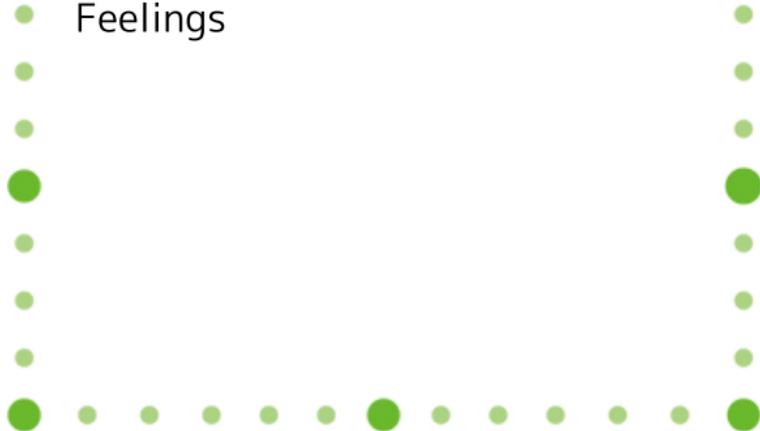
# When baby first comes home



Sibling feelings



Feelings



# DAILY SCHEDULE

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TIME	SCHEDULE
NOTES	

# WEEKLY Schedule

Monday

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Tuesday

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Wednesday

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Saturday & Sunday

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# Medical Care Management



It is not uncommon for children with Trisomy 18 to retain many complications and have to visit many medical departments. Please consult with your primary care doctor as it may fall under the category of Specific Pediatric Chronic Diseases.

The children may suddenly become ill. In such cases, it is extremely important to consider in advance what specific arrangements should be made for a hospital visit.

The pediatrician will be the center of this process, but it is also important to summarize the current situation and treatment plan for each organ for the future, as it may not be possible to do it at only one hospital.

The situation will probably change depending on whether the children have surgery or not and growing.

It is also important to keep an up-to-date summary of the situation in case there are any changes in the way of handling. By keeping these records, it may give you a chance to feel their growth, and it will also be useful when it becomes difficult to provide normal medical care due to disasters.

In daily life, we may need to keep an eye on medication management at home, nutritional status (including the actual method of oral and liquid nutrition), and breathing status such as oxygen administration.

As they grow, their management situation will change, so it is important to check with the primary care doctor on the appropriate situation.

# Medical Care Management



In addition to the above, it is also important to be aware of your family's physical and mental health.

It is just as important for the family to think about their children as it is for them to think about their own mental well-being.

For this purpose, you may want to consider using welfare resources such as home nursing and home care.

For applications for Special child dependent allowance, Children's Disability Welfare Allowance, certificate of intellectual disability, physical disability certificate, and beneficiary certificate, please consider consulting with the disability welfare section of your local municipality.

It is also a good idea to consult with family associations and support groups.

It is essential that both you and your family keep in mind that you must lead a life that is physically and mentally comfortable.



# About Rehabilitation



Rehabilitation includes physical therapy (PT), occupational therapy (OT), speech-language-hearing therapy (ST), baby gymnastics, and swallowing training, etc.

PT is an area that focuses on coarse motor activities such as moving and maintaining posture, OT on fine motor activities such as daily activities, and ST on improving communication. Swallowing training is often done as part of ST under the evaluation and guidance of an ENT doctor or dentist. Rather than doing all of these at the same time, there are often choices to be made, usually starting with PT depending on the child's developmental status.

There are public rehabilitation facilities in prefectures, cities, towns and villages, as well as private rehabilitation facilities and visiting rehabilitation systems.

It is best to consult with your doctor about which rehabilitation facility is best to use.



## About Rehabilitation



The significance of rehabilitation is not only to improve the child's various functions and prevent deterioration, but also to share information with other family members.

The timing of the start of rehabilitation depends on the child's situation and the situation of the rehabilitation facility.

It is best to consult with a pediatrician for heart, breathing, and spasms, and an orthopedic surgeon for hip joints, large joints in the upper and lower limbs, bone conditions, and muscle strength.

Rehabilitation does not only mean that it has to be done in a rehabilitation facility.

Depending on your child's situation and your family's living environment, it may be difficult to go to a rehabilitation facility on a regular basis.

In such a case, you may want to ask your child's PT, OT, or ST doctor to take a look at your child's current situation (evaluation) and discuss ways you can do things at home without strain.

It is important to consider the best way of rehabilitation for each child and family so that they can feel the growth of their child.







# Helpful Information



## 🌀Women's Health Support Center

There are centers in your city, town, or village where you can get advice on pregnancy, children and child rearing. The center is staffed by doctors, midwives, and public health nurses. Please feel free to visit them.

## 🌀Mother and child Health Handbook App 「BOSHIMO」

You can keep a record of your pregnancy checkups manage your child's vaccination schedule, and get information about your local area. It seems that more and more governments are introducing this system.

## 🌀Father-Son Handbook

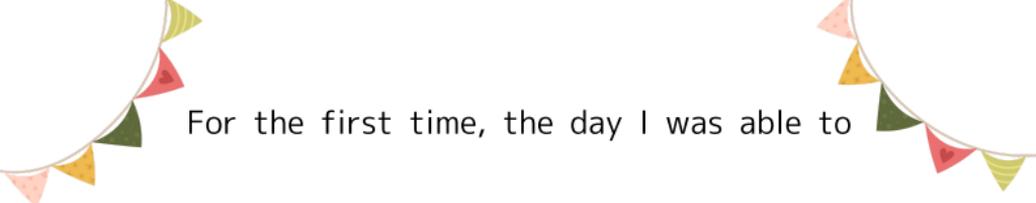
Recently, local governments have been issuing paternity handbooks for fathers. It seems to contain information on how fathers can participate in child-rearing and how to help them balance work and family life.

## 🌀Medical Information System for Children in Medical Care

Family members can enter information about medical treatment and other matters using their smartphones or computers to create a database. If you are transported to an emergency room while you are away from home, emergency personnel and the medical institution to which you are transported will be able to view the information. For details on how to apply, please visit the following website of the Ministry of Health, Labor and Welfare.

## 🌀Preparing for Disasters

Disaster preparedness handbooks include those issued by your local municipality and the "Disaster Prevention Notebook to Protect Babies and Mothers" on the Disaster Prevention. Information page of the Cabinet Office. It is a good idea to have a copy on hand for preparedness.



For the first time, the day I was able to



Memorial Day's / /



Memorial Day's / /



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Memorial Day's / /



Growth and  
Development  
Records

Keep a record of what happens at  
the hospital and at home.

1~2 months old

3~4 months old

5~6 months old

7~8 months old

9~10 months old



11~12 months old

13~15 months old

16~18 months old

19~21 months old



22~24 months old

25~27 months old

28~30 months old

31~33 months old



34~36 months old

3~4 years old

5~6 years old







# Utilizing the growth charts



Growth charts give us important information to see if your child is growing up in a healthy manner. You have probably seen them before, as those for infants and toddlers can be found in the maternal and child health handbook, and those for school-age children can be found in school report cards. When you go to your pediatrician for a checkup, your height, weight, and head circumference will probably be measured.

The measurements can be shown on a growth chart to show if your child is growing well. If there is a drop in weight, you may need to check for nutritional status or complication conditions (such as heart failure).

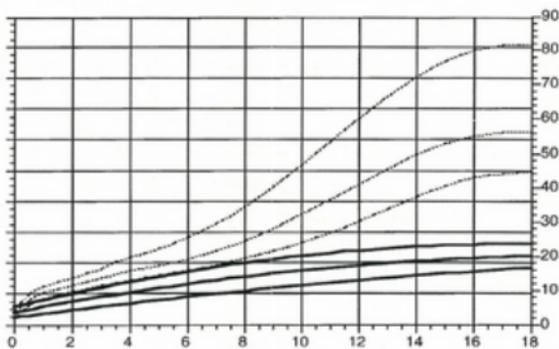
A growth chart for children with trisomy 18 is useful to determine if your child is large, normal, or small for a child with trisomy 18. The growth chart was shown in the paper published in 1994 in the American Journal of Medical Genetics (AJMG).

Dr. Carey and colleagues (Department of Pediatrics, University of Utah) summarized the research of the "Support Organization for Trisomy 18, 13, and Related Disorders, SOFT (<http://www.trisomy.org>)", a support group in the United States. The growth chart is now available on the SOFT website (<https://trisomy.org/resources/surgeries-growth-charts/>).

1) Baty BJ, Blackburn BL, Carey JC. Natural history of trisomy 18 and trisomy 13: I. Growth, physical assessment, medical histories, survival, and recurrence risk. *Am. J. Med. Genet.* 1994 Jan 15;49(2): 175-188. doi:10.1002/ajmg.1320490204. PMID:8116665

The figures from the next section are from this paper with permission from Wiley-Liss Inc.

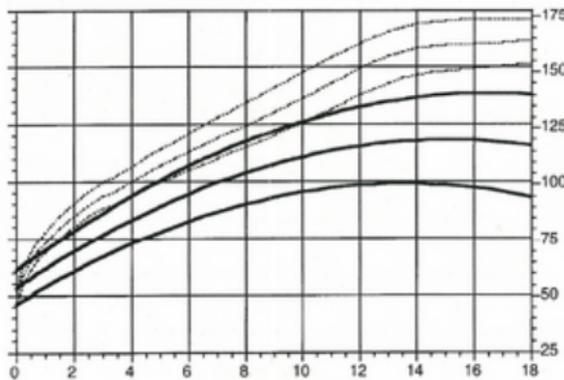
## Weight trend (men and women)



Weight (Kg)

Age (years)

## Height trend (men and women)



Height (cm)

Age (years)

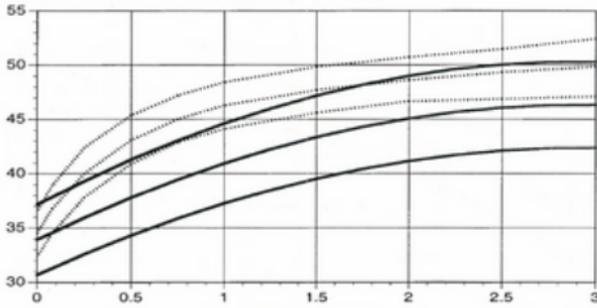
( trisomy 18 = solid lines : normal = dotted lines )



## Head circumference trend (men and women)



Head  
circumference  
(cm)



Age (years)

( trisomy 18 = solid lines : normal = dotted lines )



## Q & A



**Q:** As a father, I' m wondering how I can be involved.

**A:** You may often be asked to "support your wife". This is important, of course, but the father is also in a difficult situation. It is natural for him to feel confused and lost. That's okay. Please try to make time to spend with your baby. Try to feel the messages from your baby. Then, I hope you can share your thoughts with your mother. It is also important to have someone, such as medical staff, psychologists, or a trusted friend, take care of your shaky feelings. With the support of the people around you, I hope that you will be able to slowly build your new family.

**Q:** How do I tell my younger siblings about my baby with Trisomy 18?

**A:** Each sibling is different in age and personality, and there is no right way to tell them. The important thing is to tell them that their precious family member, the baby, was born in the mother's belly before telling them about Trisomy 18. The baby may need to be admitted to the NICU. Still, it would be nice to actually see the baby as soon as possible. Before the visit, talk to the parents and staff beforehand so that they will not be surprised by the medical equipment or the baby's condition, and welcome them with a smile. For younger children, I think it would be better to tell them about the baby slowly as their siblings grow up.

## Q & A

**Q: Can a special test during pregnancy tell me how long my baby will live?**

**A:** It is impossible to know what the future holds for your child through blood test, ultrasonography, MRI scans, or genetic tests during pregnancy.

We have a tally of life expectancy based on previous reports, but no one can know the life of your child. I think this is true for all of us, including ourselves.

**Q: Is it better to have a natural birth or a cesarean section?**

**A:** A long time ago, there were many facilities that did not perform cesarean sections even if the baby was in distress because children with Trisomy 18 were short-lived.

Even today, there are still some facilities that have such a policy. However, there are still some facilities that have such a policy.

However, it is considered paternalistic and undesirable today for medical professionals to unilaterally impose a policy of "...so ...no".

I believe that the medical staff and the family should discuss and decide what is in the best interest of the child, including whether or not to have a C-section.



## Q & A



### Q: What should I do for the time being to live at home?

A: You may need to consider medical care, rehabilitation, education, and welfare procedures for your child. Information about where you live is extremely important. It is important to keep in touch with your doctor, genetic counseling facilities, public health nurses, the Disability Welfare Division, the Children's Division, support groups, and other family members, and in some cases, it may be better for the family to proactively ask for information.

### Q: I am very worried about the future.

A: Yes, it is easy to imagine that you may feel anxious about the future,

depending on your child's health condition. There are some things that can be managed and solved by the family alone, and others that are difficult without the help of others. Family associations and support groups may be able to help with the management of the family's mind.

You may want to consider using them. More importantly, if your family member is experiencing mental or physical problems, it may be a good idea to consult your child's doctor and receive appropriate medical care through him/her.



## A Message from a Fellow Mother and Father

Children with trisomy 18 come to us thinking, "It's okay to go to you guys. Don't be so hard on yourself! Have confidence in yourself!"

You may feel pain and suffering, but a lot of people will help you. So let's live life to the fullest!

Thank you for being born. The time we spent together is an irreplaceable treasure for Mom. You are an angel now, but please stay close to me.

I had a lot of anxiety at first, but thank you for choosing me. I love you so much because you have your own pace.

You are the strongest person in your little body, and you are loved by everyone. Thank you for being born!

Don't worry about defining "normal" for yourself. You are the only one in the world who matters.

Thank you for being born! Every day is a treasure with you living each day to the fullest!

Children with trisomy 18 have their own pace. They may be small or slow, but they are definitely growing every day.

## A Message from a Fellow Mother and Father

There will come a time when the days of trying to survive will be replaced by the joy of nurturing. It's okay, it's okay. Don't be overwhelmed by despair! All children grow up with the help of the people around them. You can laugh, you can cry, you can be angry. You and I, let's live our lives, cherishing the little things in life, envisioning the future one centimeter ahead of now! You're not alone!

Thank you for being born! I'm looking forward to the day when we can all live together. I'm looking forward to the day when we can all live together.

Thank you for being born into our family. I'll never forget how you grew up in my belly for about eight months. I will deepen the meaning of what you have taught me, and live in a way that will be praised by you so that we can fulfill our family's mission.

Manaka, when I first held you in my arms, I couldn't stop crying at the weight of your tiny body.

Even with their small bodies, these children are positive about living to the fullest. Please take their lives in your hands.

## Message from a sibling

It wants you to play vigorously now on.  
I love you.

Why are you so cute? Thank you for making me your sister.  
I love you. I can smell the warmth of the sun for you,  
Mizuki. I know this because I am your sister★  
Mizuki is my little brother. I love you.

I can't wait to see you. (15 years old brother)  
Get well soon. (5 years old brother)

Thank you for being born from my mom.  
Your oldest brother (age 7, from first grade)

If you had lived...  
I thought of all the things I would have done for you.  
I'm working at a welfare center now. (older brother)





# Introduction to Trisomy 18 Support Group

<https://18trisomy.com/>

## ◇Type's of members

Family Members / children with trisomy 18 and their families

Supporting Members /

Medical and welfare professionals who support the trisomy 18 Association.

## ◇Dues

Regardless of the month of admission ; annual membership fee is 1000 yen.

## ◇Activity

\*offline meeting 「Free Place」

We provide a place where people can talk and interact freely without setting at them.

It will be held in various locations around the country or online.

\*News letter

Information about your child, medical information, books, etc.

\*Peer counseling

Consultation and support, We're matching members.

\*Publishing

\*Cooperation with medical professionals.

We communicate with medical professionals, participate in conferences and other events, and express our opinions from the perspective of families.

We also collaborate with information on medical care and rehabilitation.

## A book all about "Trisomy 18"

"Trisomy 18: Toward Better Medical Care and Family Support for Children"

Hiroko Sakurai, Yoko Hashimoto and Tomoki Kosho, Editor  
MEDICUS SHUPPAN, Publishers Co., Ltd./4180 yen



# CONTACT.



Personal physician

Hospitals

Pharmacy

Home nursing station

School



## Trisomy 18 Support Group

Date of issue: October, 2021

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We received a grant from the Kiguchi Welfare Foundation to create the handbook.