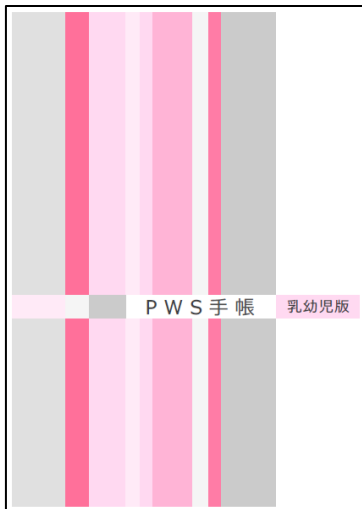


# Developing the PWS Health Handbook for Infants, Toddlers, and Preschool Children

## Personal Development Record



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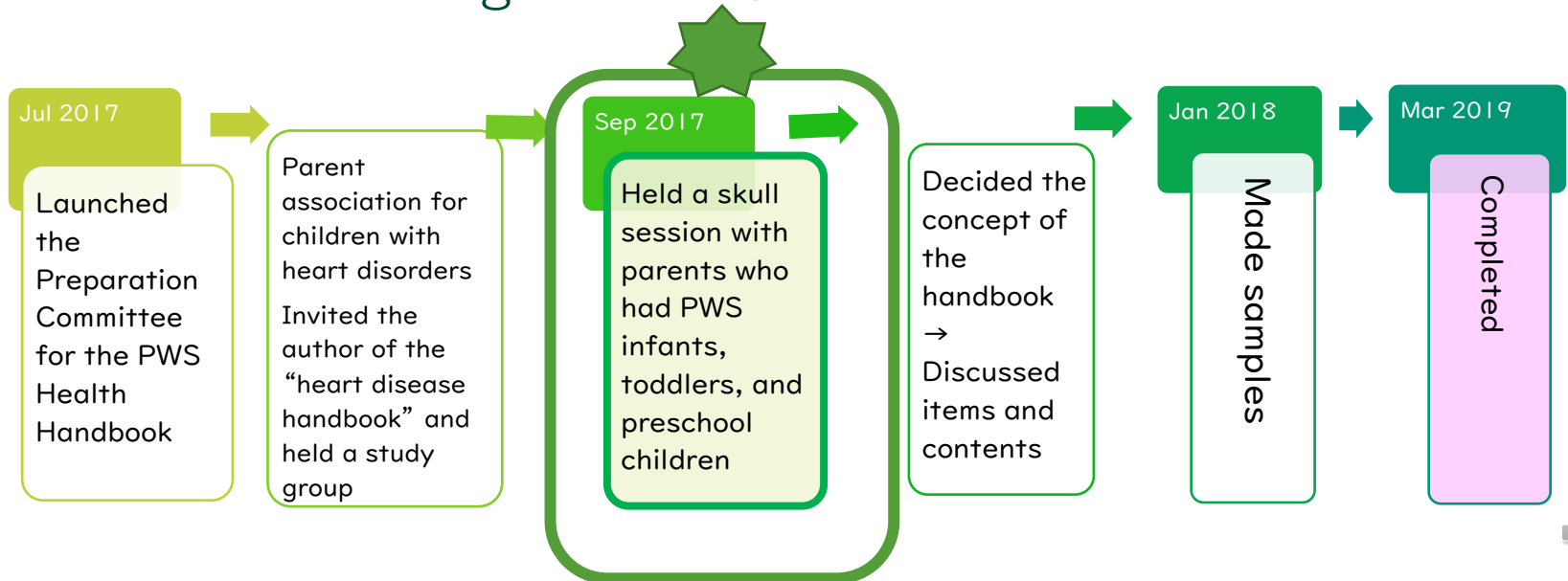
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# I. Background of the PWS Health Handbook

Parents of children with PWS become aware of the disorder called PWS for the first time through their children. They live with constant worries about whether their children are growing-up well, what they should provide their children, and whether their ways of raising children are adequate. Therefore, in addition to a maternal and child health handbook and books about childcare, we thought that it was necessary to develop a tool to guide the parents on how to raise children with PWS for the first time and provide a deeper understanding of their individuality to other people than their parents.

# II. Process of Making the PWS Health Handbook



# ★ Process of developing the handbook Exchanging opinions with 16 parents raising infants, toddlers, and preschool children with PWS

## 1. Medical and welfare history

Hospitals: genetics, pediatrics, neonatology, endocrinology, orthopedics, urology, rehabilitation, ophthalmology, and dentistry

Private child development support services, home-visit rehabilitation, and home-visit nursing

## 2. Background of visiting the hospitals and rehabilitation centers

- Introduced by a pediatrician/doctor of the hospital where the child was born as well as by welfare division staff from a ward office
- Searched by the parents themselves e.g., asked the doctor to introduce a rehabilitation center
- Introduced by an experienced mother who had raised a child with PWS

## 3. Those who supported the child other than the medical staff

- Childcare support center, child development support facility, children's center, library, public officers, nursery nurses, caseworkers, and consultation support staff.
- Grandparents, relatives, friends, friends of mothers, private lesson teachers, and volunteers

# 4. Concerns and challenges in child raising

**No information available**

- Do not know about the disorder
- Having only biased information that children with PWS become obese.

**How to give nutrition**

Weak suckling, how to give baby food/toddler meal, hydration

**Developmental delay**

- Being quiet (not crying when diaper is dirty or when they are hungry)
- Feeling anxious compared to healthy infants and other infants with PWS.

**Treatment choice**

Growth hormone, selection of hospitals and rehabilitation and nursing facilities

**Siblings**

How to treat siblings

**Understanding of PWS by surrounding people**

Understanding from grandparents, rarely known disorder

Need to frequently explain about PWS

**No one to consult with**

Having no close friend who has longer experience of raising a child with PWS

**Dental health maintenance**

Cavity

**Self-harm**

How to handle harming self and others

**Preschool**

Worry about entering a nursery school, choosing a nursery school

## 5. Necessary and relevant information for child raising

Childcare during infant, toddler and preschool years	Skills of breastfeeding, how to select a feeding bottle, baby exercises
Everyday life	How children with PWS spend every day
Child's development prospects	Information about children with PWS of the same age or slightly older
Medical treatment and <i>ryoiku</i> (comprehensive support and intervention)	<ul style="list-style-type: none"><li>• Information on when and what is needed/schedule of visiting hospital</li><li>• PWS-specialized medical facility, rehabilitation center, <i>ryoiku</i> facility</li><li>• Growth hormone</li></ul>
Social system/welfare	Social security etc., applying for a special education record book
Preschool	Preschool that can accept children with PWS
Information sharing/social gathering	Parents of children with PWS, social gathering to meet other parents with children of the same age

## 6. Sources of information

Social media

Archives published by PWS Japan

Advices from doctors, medical books

# A short summary: current situation of raising infants, toddlers, and preschool children with PWS

- They visited multiple departments of hospitals from birth
- Parents had a connection not only with medial staff but also with non-medical persons who were not necessarily familiar with PWS. Parents received advice on child raising in general and special care, except for PWS, based on their experiences.
- Information on PWS was limited even if their children were diagnosed with the disorder.  
Parents searched for information by themselves if necessary.
- Their children's development was delayed, for example, they did not drink, hold the head up, and walk by themselves.
- Parents were depressed when comparing their child with other children
- Parents could regain hope when they learnt about the child's development prospects.



Concept of the handbook =

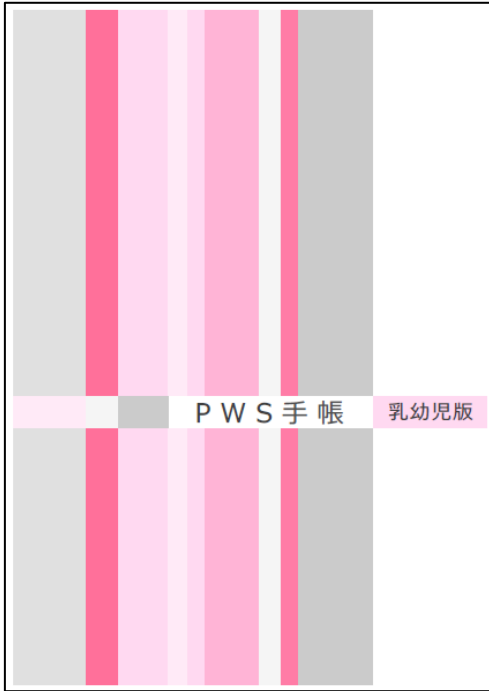
“personal development record” + “guidepost”

Many people involved have an understanding about a child with PWS.

People can learn necessary knowledge and information, whenever needed, with crucial points.

Parents can know about the pace of child development with prospects.

# III. Contents of the PWS Health Handbook



PWS Health Handbook  
(A6, 38 pages)

- Fit in a hand
- Can be kept with a maternal and child health handbook
- Hard and durable

## Contents

- Purposes of the PWS Health Handbook (for infants, toddlers, and preschool children)
- Growth during infant, toddler, and preschool years
- Birth and neonatal records
- Diagnosis of PWS
- Records of your child's growth and memories
- Medical history
- Note of your child's growth
- Preschool consultation
- Social system/welfare
- Q & A



# Purposes of the PWS Health Handbook (for infants, toddlers, and preschool children)

## Contents

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## To the parents who have a child diagnosed with PWS

### Purposes of the PWS Health Handbook

1. This handbook is to prepare your child to receive support from many people.

○ In the future,

- Your child will receive support from your parents, friends, neighbors, nursery nurses, teachers, etc. other than the parents.
- Primary caretakers will be changed from the parents to others (siblings, facility support staff, adult guardian, etc.)

○ What is important for that time

- To record a history of your child's growth
- To record the date when your child was diagnosed with PWS.
- To record how your child's health was managed

2. Your child will know how he/she has grown up as well as how much he/she was loved by the parents.



# Growth during infant, toddler, and preschool years

## Contents

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## An excerpt from the handbook

### ● Weak muscles ●

Children with PWS have difficulty in suckling at first.

Feeding difficulty may be supported by a feeding tube (milk is carried directly to the stomach by the tube going through the nose). After that, children with PWS are able to drink by mouth.

Regarding nutrition before school age, you should take care not to “feed too much” as it can cause obesity. Also, keep in mind that “extreme restriction on food intake” can affect mental and physical development.



**Give your child the nutrition they need.**



# Records (birth, diagnosis, and treatment)

## Contents

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- **Medical history**
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## Birth and neonatal records

- Attach memorable photos
- Birth records

## Diagnosis of PWS

Date when they were informed about the diagnosis, type of PWS, name of hospital that diagnosed the condition, what they were told regarding PWS  
name of doctor, departments introduced

## Medical history

- GH treatment
- Scoliosis treatment
- Other medical history

## Treatment (GH, scoliosis, etc.)

Start date: YYYY/MM/DD  
(      years      months old)  
Name of hospital:  
Name of doctor:

### Explanation about treatment

Reasons to start  
①Physique at the start  
②Examination results at the start  
  
Effects of the treatment  
Risks of the treatment  
Expected duration of the treatment

## Medical Records

	Date	In/out-patient	Contents of the treatment
1			
2			
3			

# Records (child's growth and memories)

## Contents

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- **Ability to eat by oneself e.g.)**
- Maintenance of teeth (dental consultation, nutritional guidance)
- Ability to do a physical activity (motor development)
- Favorite (physical) play
- Ability of expression
- Favorite (expressional) play

## An excerpt from the handbook

Your child will grow with individuality even after being diagnosed with PWS. Therefore, you may want to take note of your child's growth.

### ● Ability to eat by oneself ●

Your child will go through the process of breastfeeding and eating baby food slowly. Eating is a daily thing; therefore, please get support from your parents and family.

Tube feeding (feeding breast milk and baby formula through a tube)

- When it started:
- Memories:

Oral intake (drinking breast milk and baby formula by mouth)

- When it started:
- Memories:

# Information (school/social welfare/Q&A)

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- Note of your child's growth
- **Preschool consultation**
- **Social system/welfare**
- **Q & A**

### School entry consultation

Date Support center/Consultant/Contents of consultation

### Social system/Welfare

Special education record book, special child support allowance, children's welfare allowance, medical welfare benefits, specific pediatric chronic diseases, contact information

## Q&A

### Q&A

- Q. What should I do when my baby cannot drink milk well?
- Q. How should I proceed with baby food?
- Q. I worry about the relationship between my child with PWS with siblings.
- Q. I want to talk to other families having children with PWS.

## Conclusion

Our goal is that all children with PWS and their families live their lives authentically with dignity and enjoy every single day.

Currently, the PWS Health Handbook is distributed all over the country to the members of PWSA Japan and non-member parents who wish to have one. We will continuously promote the handbook for parents who raise children with PWS and revise it according to their needs.

### Acknowledgement

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