

# Current status of specific pediatric chronic diseases in Japan: National measures, disease types, treatment availability, copayment assistance, and research

Tatsuo Sawakami\*

Center for Clinical Sciences, National Center for Global Health and Medicine, Tokyo, Japan.

**SUMMARY** In Japan, specific pediatric chronic diseases include 788 diseases in 16 groups of diseases, 278 categories, and 845 subcategories as of November 1, 2021. The national specific pediatric chronic diseases measures – also called the Medical Aid Program for Chronic Pediatric Diseases of Specified Categories (MAPChD) – was established in Japan in 1974 and enshrined in law in 2005. Patients with specific pediatric chronic diseases can receive government support and welfare in several ways: *i)* MAPChD requires diagnosis and medical treatment at designated hospitals and by designated physicians so that patients receive optimal treatment; *ii)* the copayment rate for medical expenses is reduced to 20% and a maximum is set depending on household income; and *iii)* the analysis of specific pediatric chronic diseases from different perspectives is continuously being promoted. In addition to these three aspects, various measures are being implemented to provide ongoing support for patients with specific pediatric chronic diseases as they grow up.

**Keywords** specific pediatric chronic diseases, Japan, Medical Aid Program for Chronic Pediatric Diseases of Specified Categories (MAPChD)

## 1. Introduction

In Japan, specific pediatric chronic diseases must meet the following conditions as specified by the Ministry of Health, Labor, and Welfare: *i)* the disease must be chronic, *ii)* the disease must be life-threatening, *iii)* the disease must have symptoms and treatment that reduce the patient's quality of life over a prolonged period, *iv)* the disease must cause a prolonged burden and involve expensive care, and *v)* affect children under 18 years of age (including those under 20 years of age if they continue to require treatment after reaching 18 years of age) (1).

The national specific pediatric chronic diseases measures – also called the Medical Aid Program for Chronic Pediatric Diseases of Specified Categories (MAPChD) – was established in Japan in 1974 and enshrined in law in 2005 under the Child Welfare Act (2). Initially, the program covered nine groups of diseases including inborn errors of metabolism, hemophilia, pediatric cancer, chronic nephritis and nephrotic syndrome, pediatric asthma, diabetes, collagen diseases, chronic heart diseases, and endocrine diseases. The number of covered diseases has increased (3). As of November 1, 2021, the MAPChD covered 788 diseases

in 16 groups of diseases, 278 categories, and 845 subcategories (4).

MAPChD provides support for patients and families in various ways, including designated hospitals, designated physicians, and specified copayments. Financial assistance for medical expenses can significantly reduce the financial burden on patients and their families. As medical technology makes significant advances, research is being focused on various aspects including the patient's living conditions, information and communication technology (ICT) applications, and improvement of the patient's quality of life.

Here, the current status of specific pediatric chronic diseases in Japan is described in terms of national measures, disease types, treatment availability, copayment assistance, and research.

## 2. Development of national measures for specific pediatric chronic diseases in Japan and classification of those diseases

### 2.1. Development of the national measures

In Japan, the medical benefits program for pediatric diseases began in 1968 that for inborn errors of

metabolism, then for hemophilia that began in 1969. The project to research the treatment for pediatric cancer was started in 1971, for chronic nephritis and nephrotic syndrome and for pediatric asthma in 1972 (Table 1).

By integrating above programs and projects, the national specific pediatric chronic diseases measures (also called MAPChD) were established in Japan in 1974, which covers nine groups of diseases including inborn errors of metabolism, hemophilia, pediatric cancer, chronic nephritis and nephrotic syndrome, pediatric asthma, diabetes, collagen diseases, chronic heart diseases, and endocrine diseases (5). The number of diseases covered has increased. As of November 1, 2021, the MAPChD covered 788 diseases in 16 groups of diseases, 278 categories, and 845 subcategories (4).

## 2.2. Classification of specific pediatric chronic diseases

Specific pediatric chronic diseases in Japan currently include 788 diseases in 16 groups of diseases. Details on the groups of diseases, categories, and subcategories are shown in Table 2.

The 16 groups of diseases include: *i)* malignant neoplasms, *ii)* chronic kidney diseases, *iii)* chronic respiratory diseases, *iv)* chronic heart diseases, *v)* endocrine diseases, *vi)* connective tissue diseases, *vii)* diabetes mellitus, *viii)* inborn errors of metabolism, *ix)* hematologic diseases, *x)* immune diseases, *xi)* neuromuscular diseases, *xii)* chronic digestive disorders, *xiii)* a syndrome involving chromosomal or genetic alterations, *xiv)* skin diseases, *xv)* skeletal dysplasia, and

**Table 1. Development of national measures to combat specific pediatric chronic diseases in Japan**

Year	Program/Projects	Details
1968	Medical Benefits Program	A medical benefits program for inborn errors of metabolism is started.
1969	Medical Benefits Program	A medical benefits program for hemophilia is started.
1971	Project to Research Treatment	A project to research the treatment of childhood cancer is started.
1972	Project to Research Treatment	A project to research the treatment of chronic nephritis and nephrotic syndrome and a project to research the treatment of pediatric asthma are started.
1974	Program for Research into the Treatment of specific pediatric chronic diseases	The Program is created to cover 9 groups of diseases by integrating the disease-specific projects listed above and by adding diabetes, collagen diseases, chronic heart diseases, and endocrine diseases.
2005	Medical Aid Program for Chronic Pediatric Diseases of Specified Categories (MAPChD) is enshrined in law	As of April 1, 2005, the Program was moved under the Child Welfare Act and its content was modified. In addition to its expansion to 11 groups of diseases, the criteria for specified chronic pediatric diseases (symptoms of the diseases) and a medical copayment based on household income were included.
2021	List Update of MAPChD	26 diseases are added to the list; the MAPChD covers 788 diseases (without comprehensive diseases*) in 16 groups of diseases.

\*A comprehensive disease is a single name for a concept pertaining to a large number of disease groups.

**Table 2. The number of specific pediatric chronic diseases in Japan (category and subcategory)**

No.	Disease group	Category	Subcategory
I	Malignant neoplasm	6	91
II	Chronic kidney disease	21	51
III	Chronic respiratory disease	12	14
IV	Chronic heart disease	67	99
V	Endocrine disease	41	92
VI	Connective tissue disease	5	24
VII	Diabetes mellitus	1	7
VIII	Inborn error of metabolism	14	138
IX	Hematologic disease	26	52
X	Immune disease	11	56
XI	Neuromuscular disease	41	100
XII	Chronic digestive disease	16	44
XIII	Syndrome involving chromosomal or genetic alterations	1	35
XIV	Skin disease	11	16
XV	Skeletal dysplasia	2	17
XVI	Vascular disease	3	9
Total		278	845

Data source: Reference 4.

**Table 3. Criteria and maximum copayment limit based on the household tax and annual income for patients with specific pediatric chronic diseases**

Classification	Criteria based on the household's residence tax and annual income	Maximum copayment (Japanese yen)		
		Regular	Severe*	Mechanical support such as a ventilator
Household on welfare		0	0	0
Low income I	Household exempt from residence tax (Annual income of less than 800,000 Japanese yen)	1,250	1,250	500
Low income II	Household exempt from residence tax (Annual income less than 2,000,000 Japanese yen)	2,500	2,500	
General income I	Residence tax of less than 71,000 Japanese yen (Annual income of less than 4,300,000 Japanese yen)	5,000	2,500	
General income II	Residence tax of less than 251,000 Japanese yen (Annual income of less than 8,500,000 Japanese yen)	10,000	5,000	
High income	Residence tax of more than 251,000 Japanese yen (Annual income of more than 8,500,000 Japanese yen)	15,000	1,000	
Meals during hospitalization		50% of expenses		

\*"Severe" refers to: A patient with a severe condition who requires expensive medical care for a prolonged period; this is a patient whose monthly medical expenses exceed 50,000 Japanese yen more than 6 times in one year.

xvi) vascular diseases.

### 3. Designated physicians and designated hospitals for specific pediatric chronic diseases in Japan

In order to promote diagnosis and treatment accessibility for patients with specific pediatric chronic diseases, measures to designate physicians and hospitals were implemented in Japan. These measures play an important role in early diagnosis, early treatment, and reduction of the medical burden.

The designated physicians need to have at least five years of experience in the diagnosis or treatment of the disease and be certified by a relevant medical society or complete training required by government. The designated hospitals are medical facilities that have sufficient capacity to respond to the specific pediatric chronic diseases and that have designated physicians on staff and appropriate equipment available. Enacted on January 1, 2015, the Partial Amendment of the Child Welfare Act stipulates that when a patient with a specific pediatric chronic disease applies for assistance with medical expenses, the application form (medical certificate) must be completed by a designated physician.

Information on designated physicians and designated hospitals for specific pediatric chronic diseases are published by local governments. For instance, 3,304 designated physicians and 1,474 designated hospitals in Tokyo are listed with the Bureau Social Welfare and Public Health of the Tokyo Metropolitan Government as of August 31, 2021 (6).

### 4. Assistance with medical expenses related to specific pediatric chronic diseases in Japan

When a patient is diagnosed with a specific pediatric

chronic disease by a designated physician, the patient can apply for the assistance with medical expenses from the MAPChD in order to reduce the financial burden on patients and their families. In Japan, the copayment rate for specific pediatric chronic diseases has been reduced from 30% to 20%, and a maximum is set depending on household income (7).

MAPChD has six classes that determine the maximum copayment based on the household's residence tax and annual income (Table 3): *i*) a household on welfare that is exempt from medical expenses according to the Ministry of Health, Labor and Welfare; *ii*) low income I, which is a household with annual income of less than 800,000 Japanese yen that is exempt from residence tax; *iii*) low income II, which is a household with an annual income of less than 2,000,000 Japanese yen that is exempt from residence tax; *iv*) general income I, which is a household with an annual income of less than 4,300,000 Japanese yen that is subject to residence tax of less than 71,000 Japanese yen; *v*) general income II, which is a household with an annual income of less than 8,500,000 Japanese yen that is subject to residence tax of less than 251,000 Japanese yen; and *vi*) high income, which is a household with an annual income of more than 8,500,000 Japanese yen that is subject to residence tax of more than 251,000 Japanese yen.

The copayment is free for a household on welfare. The maximum limit of copayment is 1,250 – 15,000 Japanese yen for general patients, depending on the household's residence tax and annual income.

### 5. Research on specific pediatric chronic diseases in Japan

As medical technology makes significant advances, research is being focused on various aspects including

**Table 4. The major research programs promoted by the Information Center for Specific Pediatric Chronic Diseases in Japan in 2020**

Research direction	Research content
Online resources	<ul style="list-style-type: none"> <li>① Creating websites for the general public with content explaining specific pediatric chronic diseases to patients and their families.</li> <li>② Studying visits to the Center's portal and its dissemination of information.</li> <li>③ Studying content for children (videos)</li> </ul>
Collation of patient data	<ul style="list-style-type: none"> <li>① Studying the coding of specific pediatric chronic diseases based on ICD-10.</li> <li>② Guidelines for the use of registry data by academia and the private sector, how consent should be obtained, and guidelines on the handling of past registry data.</li> <li>③ Studying registration in the database for children with s specific pediatric chronic diseases (2015-2018).</li> <li>④ Design and development of a registry database and improvement of its accuracy.</li> </ul>
Financial burden of patient treatment	Research on the medico-economic value of pediatric treatment
Patient quality of life	<ul style="list-style-type: none"> <li>① Support for children with specific pediatric chronic diseases using the International Classification of Functioning in Life (ICF).</li> <li>② Organizing disability welfare policies and systems from the patients' perspective: An attempt to provide information using ICT.</li> </ul>
National measures	<ul style="list-style-type: none"> <li>① A study to create and conduct a training program (e-learning) for specialists in specific pediatric chronic diseases.</li> <li>② A study on measures for specific pediatric chronic diseases in coordination with the Japanese Society of Pediatrics and its subcommittees and related academic societies.</li> <li>③ A study on specific pediatric chronic diseases that may qualify as designated intractable diseases.</li> </ul>
Follow-on support	<ul style="list-style-type: none"> <li>① A study on support for the independence of patients with specific pediatric chronic diseases; ascertaining the status of social participation after adulthood.</li> <li>② A study on support for the independence of patients with specific pediatric chronic diseases: Revision of the guidelines on transition assistance for patients with specific pediatric chronic diseases.</li> </ul>

Data source: *Reference 8.*

the patient's living conditions, ICT applications, and improvement of the patient's quality of life.

For instance, research groups at the Information Center for Specific Pediatric Chronic Diseases in Japan are conducting research on aspects such as provision of information, collation of patient data, assessment of financial burdens, and follow-on support. The research conducted in 2020 is summarized in Table 4, and research was conducted in the following main areas: *i)* online resources; *ii)* collation of patient data; *iii)* the financial burden of patient treatment; *iv)* patient quality of life; *v)* national measures; and *vi)* follow-on support.

## 6. Perspectives for the future

In Japan, patients with specific pediatric chronic diseases can receive government support and welfare from designated physicians and designated hospitals and assistance with medical expenses. In addition, specific pediatric chronic diseases are being researched. That said, more attention needs to be paid to follow-on support for patients with specific pediatric chronic diseases, such as disease progression with age or the development of sequelae (9). Some patients have difficulty entering the workforce, which leads to an increased psychological and financial burden on the patient and the patient's family (10). National measures to combat specific pediatric chronic diseases and the continued enhancement of those

measures are expected to help more patients to benefit from treatment availability, copayment assistance, research, and follow-on support.

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\*Address correspondence to:

Tatsuo Sawakami, Center for Clinical Sciences, National Center for Global Health and Medicine, 1-21-1 Toyama, Shinjuku, Tokyo 162-8655, Japan.

E-mail: [tsawakami@hosp.ncgm.go.jp](mailto:tsawakami@hosp.ncgm.go.jp)

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