



Hemopoietic Cell Transplant Patients' Booklet



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Introduction

Hematopoietic stem cell transplantation is commonly carried out as a radical treatment for intractable blood diseases, and the number of long-term transplant survivors has been steadily increasing. Nevertheless, along with this increase, it has become clear that long-term transplant survivors have higher risks for cardiovascular disease, secondary malignancies, and infectious diseases, etc. as compared to persons of the same age who have not undergone such transplantation. As such, it is important for all post-transplant patients to receive regular, long-term, thorough health management. Since long-term follow-up and health management after hematopoietic stem cell transplantation are not special, they can therefore be suitably performed at not only the transplant facility but also at regional medical institutions, clinics, and health management centers.

The aim of this booklet is to maintain the long-term health of post-transplant patients through collaboration with transplant facilities by sharing specific key points related to post-transplant health management, such as medical information of transplant patients, prevention of lifestyle-related diseases, early detection of cancer, and vaccinations. We hope that all of you could understand the whole idea of this booklet, and that we can help patients received hematopoietic stem cell transplantations.

*** This schedule of vaccination in this booklet is written based on the frequency of viral infections and schedule for immunization IN JAPAN. When you use this booklet outside Japan, you should change the contents according to national and professional society Guidelines in your country.**



For the supervisor at the transplant facility

This booklet provides information that makes the transplant course and the status of patients clear, so that primary care physician can understand them when such patients receive examinations at medical institutions other than transplant facility. It also covers how to contact and consult with the transplant facility, when necessary.

Before giving this booklet to patients, please completely fill out the following sections: (1) “Your profile” (Page 8), (2) “Your transplant facility” (Page 9), and (3) “Transplant record” (Page 10).

In the case that both the transplant facility and the primary care physician will be performing follow-ups, please make use of subsections (6) “Record of entering and leaving the hospital”, (8) “Recent condition”, and (9) “Vaccinations”.

For patients (How to use this booklet)

- This booklet is given to persons who have undergone allogeneic hematopoietic stem cell transplantation.
- When you receive this booklet, please fill out your profile in the section entitled “Profile,” (Page 8) and check the details in the “Transplant record” (Page 10). “Transplant facility” (Page 9), includes important information that will make it possible for your primary care physician to contact the transplant facility. Please ask a staff member of the transplant facility to complete the sections.
- When going to see doctors at a medical institution or receiving a health checkup, please show this booklet and tell the physician that you have received hematopoietic stem cell transplantation.
- Since this booklet contains important information regarding your health, please keep it in a safe place and be very careful not to lose it.
- Information on vaccinations after transplantation is provided in the Guidelines by the academic society. Please refer to the Guidelines and when receiving any vaccinations, please make sure to consult with your primary physician.



For primary care physician

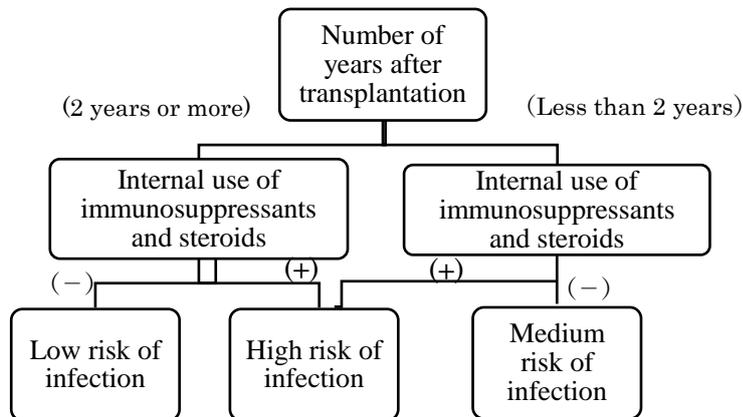
[Aim of this booklet]

This booklet has been prepared to share the health status of patients who have undergone hematopoietic stem cell transplantation with doctors involved in the health management of such patients at regional medical institutions, clinics, or health management centers.

[Overview of hematopoietic stem cell transplantation and background of this booklet]

Allogeneic hematopoietic stem cell transplantation is carried out with the objective of radically curing intractable blood diseases. Immediately after “preliminary treatment,” which is treatment with anticancer drugs and radiation therapy at levels much higher than usual, the patient receives hematopoietic stem cells from a donor. After the transplantation, the patient receives immunosuppressant drugs for a certain period of time in order to prevent a transplant immune reaction called GVHD*, where the lymphocytes of the donor attack the patient. Sometimes post-transplant patients develop life-threatening complications, such as malignant tumors (secondary cancer) and cardiovascular complications, resulting from strong treatments before the transplantation, immune reactions, or its treatments. It is well known that the frequencies of such disease in transplantation patients are higher than those in others of the same age, who have not undergone transplantation. It is therefore extremely important to carry out screenings for cancers and lifestyle-related diseases. It is also important to conduct anti-smoking education. In light of this background, we prepared this booklet in the hope that primary care physicians will assist with the long-term health management of post-transplant patients.

[Medical examinations for post-transplant patients]



- The general treatments for colds and cavities will be acceptable in a similar manner for non-transplant patients.

- Special consideration is needed with regard to infectious diseases.
- If there are signs such as sustained fever, respiratory symptoms (coughing, dyspnea, respiratory discomfort), decreased blood pressure, decreased oxygenation, or rashes spread widely over the body, please contact the transplant facility (Page 9).

As shown in the diagram above, the risk of infectious diseases differs depending on the post-transplant period among patients. Many of the patients with whom we ask primary care physicians to follow-up are persons who have stopped taking immunosuppressant drugs, have a stabilized post-transplant immune reaction, and do not show signs of a relapse of their original disease. In the case of such patients, with the exception of highly invasive surgeries, blood transfusions (see Page 10 regarding blood type) in post-transplant patients do not require special distinction for clinical examination. Please keep in mind the following items:

- Handling of infectious diseases

Post-transplant patients may be taking immunosuppressant drugs for *GVHD prevention and/or treatment when they visit your hospital or clinic for an examination. (This refers to patients at medium to high risk for infectious diseases in the diagram on the previous page.) If they have a fever at the time of the examination, they may be suffering from sepsis or pneumonia. In this case, please contact the transplant facility on Page 8 of this booklet, as special consideration will be required.

- Potential for development of malignant tumor (secondary cancer)

Please give a cancer screening about once a year.

- Potential for development of life-threatening complications such as cardiovascular

complications

If the patient has any symptoms, such as shortness of breath, sensation of chest tightness upon exertion, stiff shoulders, abdominal discomfort, sensation of coldness in the extremities, or any neurological symptoms (such as weakness of the extremities or numbness), please consider performing an X-ray, CT, MRI, and physiological (echocardiograph and respiratory function) examinations.

● Potential for having problems that are not life-threatening but have a negative impact on quality of life (QOL), such as growth disturbances and infertility

Patients will need suitable medical examinations and support throughout life after the transplantation, not only with regard to physical complications, but also emotional and psychosocial problems. These problems may include delays in returning to work, delays in recovering the ability to engage in physical activity and the ability to engage in sexual activity and sexual function, feelings of irritation and depression regarding post-transplant growth disturbances, changes in physical appearance, feelings of loss with regard to social relationships due the above factors, and uncertainty about the future due to economic considerations.

● Vaccination of transplant patients

After hematopoietic stem cell transplantation, immunological competence against viruses that the patient previously acquired (or was vaccinated for) is weakened or lost, so carrying out immunizations in accordance with a schedule is recommended. For details on vaccinations, please see Page 23 of this booklet.

● If any event (i.e. cardiovascular disease, malignant tumor, etc.) arises during your follow up, please contact the transplant facility on Pages 10 and 11 of this booklet.

If you have any questions or unsure about a judgment, please contact the transplant facility on Page 8 of this booklet.

*Graft-versus-host disease (GVHD) is a complication in which the lymphocytes of the donor attack the patient's organs and cause damage. If this develops soon after transplantation, it is referred to as "acute GVHD," which causes rashes, diarrhea, and/or hepatic disorders. "Chronic GVHD" tends to develop more than 100 days after transplantation and causes a variety of symptoms, such as skin symptoms, dryness of the eyes and mouth, joint contracture, liver damage, or lung disturbances. Thus, chronic GVHD can lead to a sustained decrease in quality of life (QOL) over many years.

(2) Transplant facility

Name of the Hospital:
Department:
Your ID:

Consultation time (: ~ :)
Telephone number: _____ ()
Department name: _____
Contact person name: _____
Affiliation: _____ Job category: _____
When the above-mentioned person in charge is absent
Contact person name: _____
Affiliation: _____ Job category: _____
Remarks

Holidays and non-work hours
Please use this contact information during emergencies.
Telephone number: _____ ()
Department name: _____
If there is a designated supervisor, the person stated below will respond.
Contact person name: _____
Affiliation: _____ Job category: _____
Remarks

(3) Transplant record

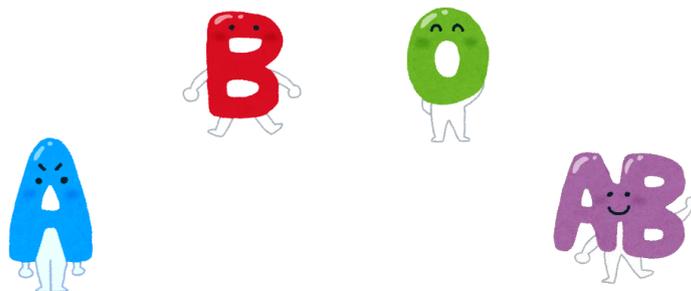
Date of transplantation: / / (dd/mm/yyyy)	
(Age of transplantation: years old)	
Disease:	
Height: cm	Weight: kg

Transplant facility
Name of the Hospital:
Department:
Your ID:
Your primary care physician:
Telephone number: ()

Donor: <input type="checkbox"/> Related <input type="checkbox"/> Unrelated
Source: <input type="checkbox"/> Bone Marrow <input type="checkbox"/> Peripheral Blood <input type="checkbox"/> Cord Blood
HLA: <input type="checkbox"/> Match <input type="checkbox"/> Mismatch <input type="checkbox"/> Haplo

Blood Type	Patient: ()	Donor: ()
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If the patient’s blood type is different from the donor’s, the patient’s blood type will ultimately change to the donor’s blood type after transplantation. Nevertheless, soon after the transplantation, the results of blood compatibility testing may be inconsistent. When performing blood transfusions, please make sure to check the blood type, and if a judgment is unclear, please contact the transplant facility.



Past transplant records: 2nd transplantation		
Date of transplantation:	/ /	(dd/mm/yyyy)
		(Age of transplantation years old)
Transplant facility:		

Donor: <input type="checkbox"/> Related <input type="checkbox"/> Unrelated
Source: <input type="checkbox"/> Bone Marrow <input type="checkbox"/> Peripheral Blood <input type="checkbox"/> Cord Blood
HLA: <input type="checkbox"/> Match <input type="checkbox"/> Mismatch <input type="checkbox"/> Haplo
Blood Type of Donor: ()

Preparative regimen, GvHD prophylaxis drug, etc.
Notices

Past transplant records: 3rd transplantation		
Date of transplantation:	/ /	(dd/mm/yyyy)
		(Age of transplantation years old)
Transplant facility:		

Donor: <input type="checkbox"/> Related <input type="checkbox"/> Unrelated
Source: <input type="checkbox"/> Bone Marrow <input type="checkbox"/> Peripheral Blood <input type="checkbox"/> Cord Blood
HLA: <input type="checkbox"/> Match <input type="checkbox"/> Mismatch <input type="checkbox"/> Haplo
Blood Type of Donor: ()

Preparative regimen, GvHD prophylaxis drug, etc.
Notices

(5) Record of lifestyle-related diseases, etc.

If a condition has newly developed, such as a lifestyle-related disease, cardiovascular disease, or cancer, please have the diagnosing doctor write the date of the diagnosis.

Disease	Date of diagnosis : dd/mm/yyyy	Name of the hospital and the doctor
Hypertension	/ /	
Carbohydrate disorder	/ /	
Diabetes	/ /	
Angina pectoris	/ /	
Myocardial infarction	/ /	
Cerebral infarction	/ /	
Cerebral hemorrhage	/ /	
	/ /	
	/ /	
	/ /	
	/ /	
	/ /	
	/ /	
	/ /	

If a stroke (cerebral infarction/cerebral hemorrhage) or a cardiovascular disease, such as a myocardial infarction, or a malignant tumor has developed, please report this to the transplant facility listed on Page 9.

(6) Record of entering and leaving the hospital

Date of hospitalization: dd/mm/yyyy
Date of discharge: dd/mm/yyyy
Purpose of this hospitalization:
Process after hospitalization (results of the examinations, treatment, complication, etc.)
Name of hospitalization facility:
Name of your primary care physician:

Date of hospitalization: dd/mm/yyyy
Date of discharge: dd/mm/yyyy
Purpose of this hospitalization:
Process after hospitalization (results of the examinations, treatment, complication, etc.)
Name of hospitalization facility:
Name of your primary care physician:

Date of hospitalization: dd/mm/yyyy
Date of discharge: dd/mm/yyyy
Purpose of this hospitalization:
Process after hospitalization (results of the examinations, treatment, complication, etc.)
Name of hospitalization facility:
Name of your primary care physician:

Date of hospitalization: dd/mm/yyyy
Date of discharge: dd/mm/yyyy
Purpose of this hospitalization:
Process after hospitalization (results of the examinations, treatment, complication, etc.)
Name of hospitalization facility:
Name of your primary care physician:

(7) Remarks for time of transfer from the transplant facility to the regional primary care physician

If the patient is being transferred from the transplant facility to the hospital of the regional primary care physician, please state below matters related to follow-up to which other physicians and/or medical professionals should pay particular attention.

(8) Recent condition

Record date: / / (dd/mm/yyyy)	Cytopenia: <input type="checkbox"/> No <input type="checkbox"/> Yes If "yes" <input type="checkbox"/> Anemia which needs blood transfusion <input type="checkbox"/> PLT less than 5x10 ⁹ /L <input type="checkbox"/> Neutrophil 0.1x10 ⁹ /L
Years after transplant: years	
Chronic GvHD: <input type="checkbox"/> No <input type="checkbox"/> Yes	
Immunosuppressant/steroid: <input type="checkbox"/> No <input type="checkbox"/> Yes	Grade of risk for infection <input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low
Notices:	

Record date: / / (dd/mm/yyyy)	Cytopenia: <input type="checkbox"/> No <input type="checkbox"/> Yes If "yes" <input type="checkbox"/> Anemia which needs blood transfusion <input type="checkbox"/> PLT less than 5x10 ⁹ /L <input type="checkbox"/> Neutrophil 0.1x10 ⁹ /L
Years after transplant: years	
Chronic GvHD: <input type="checkbox"/> No <input type="checkbox"/> Yes	
Immunosuppressant/steroid: <input type="checkbox"/> No <input type="checkbox"/> Yes	Grade of risk for infection <input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low
Notices:	

Record date: / / (dd/mm/yyyy)	Cytopenia: <input type="checkbox"/> No <input type="checkbox"/> Yes If "yes" <input type="checkbox"/> Anemia which needs blood transfusion <input type="checkbox"/> PLT less than 5x10 ⁹ /L <input type="checkbox"/> Neutrophil 0.1x10 ⁹ /L
Years after transplant: years	
Chronic GvHD: <input type="checkbox"/> No <input type="checkbox"/> Yes	
Immunosuppressant/steroid: <input type="checkbox"/> No <input type="checkbox"/> Yes	Grade of risk for infection <input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low
Notices:	

Record date: / / (dd/mm/yyyy)	Cytopenia: <input type="checkbox"/> No <input type="checkbox"/> Yes If "yes" <input type="checkbox"/> Anemia which needs blood transfusion <input type="checkbox"/> PLT less than 5x10 ⁹ /L <input type="checkbox"/> Neutrophil 0.1x10 ⁹ /L
Years after transplant: years	
Chronic GvHD: <input type="checkbox"/> No <input type="checkbox"/> Yes	
Immunosuppressant/steroid: <input type="checkbox"/> No <input type="checkbox"/> Yes	Grade of risk for infection <input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low
Notices:	

Record date: / / (dd/mm/yyyy)	Cytopenia: <input type="checkbox"/> No <input type="checkbox"/> Yes If "yes" <input type="checkbox"/> Anemia which needs blood transfusion <input type="checkbox"/> PLT less than 5x10 ⁹ /L <input type="checkbox"/> Neutrophil 0.1x10 ⁹ /L
Years after transplant: years	
Chronic GvHD: <input type="checkbox"/> No <input type="checkbox"/> Yes	
Immunosuppressant/steroid: <input type="checkbox"/> No <input type="checkbox"/> Yes	Grade of risk for infection <input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low
Notices:	

Record date: / / (dd/mm/yyyy)	Cytopenia: <input type="checkbox"/> No <input type="checkbox"/> Yes If "yes" <input type="checkbox"/> Anemia which needs blood transfusion <input type="checkbox"/> PLT less than 5x10 ⁹ /L <input type="checkbox"/> Neutrophil 0.1x10 ⁹ /L
Years after transplant: years	
Chronic GvHD: <input type="checkbox"/> No <input type="checkbox"/> Yes	
Immunosuppressant/steroid: <input type="checkbox"/> No <input type="checkbox"/> Yes	Grade of risk for infection <input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low
Notices:	

Record date: / / (dd/mm/yyyy)	Cytopenia: <input type="checkbox"/> No <input type="checkbox"/> Yes If "yes" <input type="checkbox"/> Anemia which needs blood transfusion <input type="checkbox"/> PLT less than 5x10 ⁹ /L <input type="checkbox"/> Neutrophil 0.1x10 ⁹ /L
Years after transplant: years	
Chronic GvHD: <input type="checkbox"/> No <input type="checkbox"/> Yes	
Immunosuppressant/steroid: <input type="checkbox"/> No <input type="checkbox"/> Yes	Grade of risk for infection <input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low
Notices:	

Record date: / / (dd/mm/yyyy)	Cytopenia: <input type="checkbox"/> No <input type="checkbox"/> Yes If "yes" <input type="checkbox"/> Anemia which needs blood transfusion <input type="checkbox"/> PLT less than 5x10 ⁹ /L <input type="checkbox"/> Neutrophil 0.1x10 ⁹ /L
Years after transplant: years	
Chronic GvHD: <input type="checkbox"/> No <input type="checkbox"/> Yes	
Immunosuppressant/steroid: <input type="checkbox"/> No <input type="checkbox"/> Yes	Grade of risk for infection <input type="checkbox"/> High <input type="checkbox"/> Moderate <input type="checkbox"/> Low
Notices:	

(9) Vaccinations

This schedule of vaccination is written based on the frequency of viral infections and schedule for immunization IN JAPAN. When you use this booklet outside Japan, you should change the contents according to national and professional society guidelines in your country.

Vaccinations after hematopoietic stem cell transplantation basically start with inactivated vaccines (influenza and 4-in-1 vaccines) and then shift to attenuated live vaccines. If the patient's condition is poor due to taking immunosuppressant drugs or having chronic GvHD, receiving vaccinations sometimes may not be possible. As for the actual intake schedule, please implement the vaccinations in accordance with "Vaccination requests" on Page 25.

	Names of immunization	Inoculation time	Category of vaccine
Preferred	Influenza HA	6~12 months after HSCT and have fewer exacerbations of chronic GvHD, once a year annually (November to December)	Inactivated vaccine
	Quadruple vaccine (Diphtheria, Pertussis, Tetanus, Polio(IPV))	6~12 months after HSCT and have fewer exacerbations of chronic GvHD, total three times	
	Haemophilus influenzae type b (Hib), *Pneumococcal (PCV13, PPSV23)	6~12 months after HSCT and have fewer exacerbations of chronic GvHD, total three times in every 1~3 months *only one shot for PPSV23 (Pneumovax 23)	
	MR (measles, rubella), Mumps, Varicella	Two years after HSCT, have finished taking immunosuppressants, and have fewer exacerbations of chronic GvHD, total twice	Live attenuated vaccine
As	Hepatitis B	One year after HSCT and	Inactivated

necessary		have fewer exacerbations of chronic GvHD, in case of HBV carrier in his/her family, two times in every one month and once after the six months (total three times)	vaccine
	Hepatitis A, Rabies, Japanese Encephalitis	One year after HSCT and have fewer exacerbations of chronic GvHD, in case of going to the endemic region	
Should not	Tuberculosis (BCG)	Should not be shot in every period after HSCT	Live-virus vaccine

➤ **Post-hematopoietic stem cell transplant immunization schedule (example)**

Inoculation time after HSCT (months)				
6~12	9~15	12~18	24	30
DPT-IPV	DPT-IPV	DPT-IPV	MR	MR
Hib	Hib	Hib	Varicella	Varicella
PCV13	PCV13	PCV13		
Simultaneously or separately			Simultaneously or separately	



➤ **Record of vaccinations**

When receiving a vaccination, please take this to the medical institution and have a record of the vaccination completed below.

Names of immunization	Date of immunization (dd/mm/yyyy)	Name of hospital	Production number on the vaccine
DPT-IPV			
MR			
Mumps			
Varicella			

Names of immunization	Date of immunization (dd/mm/yyyy)	Name of hospital	Production number on the vaccine
PCV 13			
PPSV23			
Hib			
Hepatitis B			
Hepatitis A			
Japanese Encephalitis			

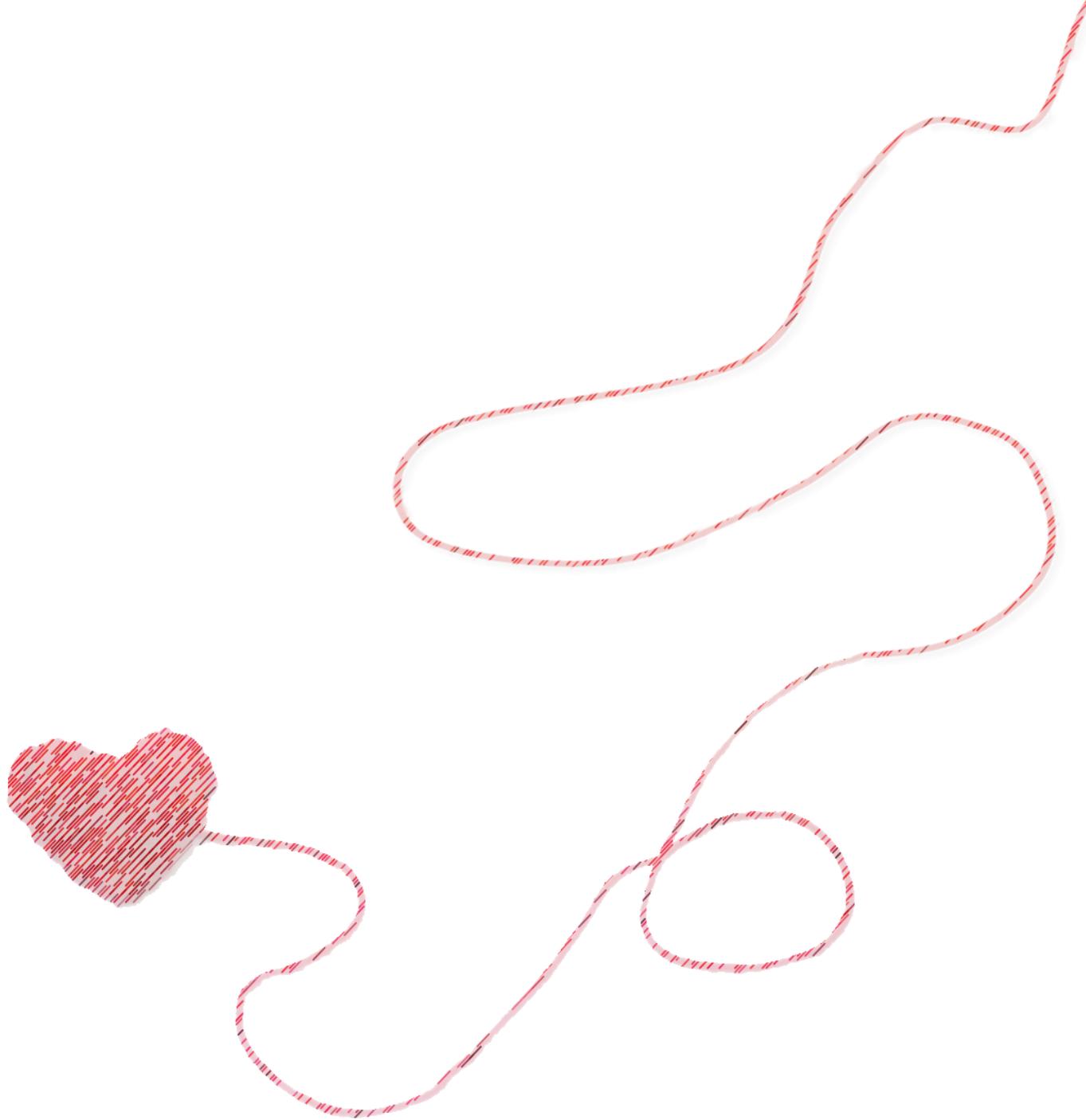
Names of immunization	Date of immunization (dd/mm/yyyy)	Name of hospital	Production number on the vaccine
Rabies			
Influenza HA			
Other			

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