

Fri. Jul 9, 2021

## Track6

International Symposium of Pediatric Heart and Lung Transplantation

### Chair Lecture

#### Struggle to save children with end-stage heart failure

Chair: Soichiro Kitamura (Japan Cardiovascular Research Foundation / National Cerebral and Cardiovascular Center, Japan)

1:00 PM - 1:35 PM Track6 (現地会場)

#### [ISPHLT-CP] Struggle to save children with end-stage heart failure

○Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

International Symposium of Pediatric Heart and Lung Transplantation

### Keynote Lecture 1

#### The world of pediatric heart transplantation from the beginning

Chair: Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

9:00 AM - 9:30 AM Track6 (現地会場)

#### [ISPHLT-KL1] The world of pediatric heart transplantation from the beginning

○Linda J Addonizio<sup>1,2</sup> (1. Pediatric Cardiology, Columbia University Vagelos College of Physicians and Surgeons, USA, 2. Morgan Stanley Children's Hospital, USA)

International Symposium of Pediatric Heart and Lung Transplantation

### Keynote Lecture 2

#### Pediatric organ donation in USA

Chair: Juntaro Ashikari (Medical Information Headquarters, Japan Organ Transplant Network, Japan)

1:45 PM - 2:15 PM Track6 (現地会場)

#### [ISPHLT-KL2] Pediatric organ donation in the United States of America

○Thomas A Nakagawa<sup>1,2</sup> (1. Division of Pediatric Critical Care Medicine, Department of Pediatrics, University of Florida College of Medicine, Jacksonville, FL, USA, 2. Carolina Donor Services, Durham, NC, USA)

International Symposium of Pediatric Heart and Lung Transplantation

### Keynote Lecture 3

#### Pediatric heart transplantation: from the beginning

Chair: Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

3:20 PM - 3:50 PM Track6 (現地会場)

#### [ISPHLT-KL3] Pediatric heart transplantation: from the beginning

○Joyce K Rusch (Cardiac Transplant, Loma Linda University, USA)

International Symposium of Pediatric Heart and Lung Transplantation

### Symposium 1

#### Current status and future aspect of pediatric heart transplantation in the world

Chair: Heima Sakaguchi (Department of Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)

Chair: Shigetoyo Kogaki (Pediatrics and Neonatology, Osaka General Medical Center, Japan)

9:40 AM - 11:00 AM Track6 (現地会場)

#### [ISPHLT-SY1-1] Pediatric heart transplantation in Brazil

○Estela Azeka (Cardiology, Heart Institute (InCor) University of Sao Paulo Medical School, Brazil)

#### [ISPHLT-SY1-2] Pediatric heart transplantation in Osaka University

○Jun Narita (Department of Pediatrics, Osaka University Graduate school of Medicine, Japan)

#### [ISPHLT-SY1-3] Pediatric heart transplantation in NCVC

○Heima Sakaguchi, Norihide Fukushima, Hajime Ichikawa, Takaya Hoashi, Yuki Ito, Hikari Miike, Kenichi Kurosaki, Isao Shiraishi (Department of Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)

#### [ISPHLT-SY1-4] National consultation system of children with end-stage heart failure in Japan

○Takahiro Shindo (Division of Cardiology, National Center for Child Health and Development, Japan)

International Symposium of Pediatric Heart and Lung Transplantation

### Symposium 2

#### Current status of pediatric organ donation in the

world

Chair:Juntaro Ashikari (Medical Information Headquarters, Japan Organ Transplant Network, Japan)  
Chair:Thomas A. Nakagawa (Division of Pediatric Critical Care Medicine, Department of Pediatrics, University of Florida College of Medicine/Medical Director,  
2:30 PM - 3:10 PM Track6 (現地会場)

#### [ISPHLT-SY2-1] Ethical issues in pediatric organ donation

○Thomas A Nakagawa<sup>1,2</sup> (1.Division of Pediatric Critical Care Medicine, Department of Pediatrics, University of Florida College of Medicine. Jacksonville, FL. USA, 2.Carolina Donor Services. Durham, NC. USA)

#### [ISPHLT-SY2-2] Pediatric organ donation and transplantation in Japan: achievements in the past decade and goals in the next

○Juntaro Ashikari (Medical Information Headquarters, Japan Organ Transplant Network, Japan)

#### [ISPHLT-SY2-3] Current status of pediatric organ donation in Japan: should organ donation from abused children be prohibited?

○Takashi Araki (Saitama Medical Center, Saitama Medical University, Japan)

### International Symposium of Pediatric Heart and Lung Transplantation Symposium 3

#### How to manage pediatric thoracic organ transplant recipient

Chair:Fumiko Mato (Center for Pediatric Diseases, Osaka University Hospital, Japan)  
Chair:Yumiko Hori (Department of Transplantation, Department of Nursing, National Cerebral and Cardiovascular Center, Japan)  
4:00 PM - 4:55 PM Track6 (現地会場)

#### [ISPHLT-SY3-1] The role of the child life specialist in the USA and Japan: the creation of a beautiful friendship

○Alison Heffer (Child Life Department, New York-Presbyterian Morgan Stanley Children's Hospital, USA)

#### [ISPHLT-SY3-2] The role of recipient transplant coordinator in pediatric heart transplantation in Japan

○Yumiko Hori<sup>1,2</sup>, Nobuaki Konishi<sup>1,2</sup>, Ayaka

Arizono<sup>1,2</sup>, Heima Sakaguchi<sup>3</sup>, Norihide

Fukushima<sup>2</sup> (1.Department of Nursing,

National Cerebral and Cardiovascular

Center, Japan, 2.Department of

Transplantation, National Cerebral and

Cardiovascular Center, Japan, 3.Department

of Pediatric Cardiology, National Cerebral

and Cardiovascular Center, Japan)

#### [ISPHLT-SY3-3] The role of child life specialists in pediatric heart transplantation in Japan: bridging the gap, serving as a buffer, and offering scaffoldings

○Fumiko Mato (Center for Pediatric Diseases, Osaka University Hospital, Japan)

### International Symposium of Pediatric Heart and Lung Transplantation

#### Special Event

Thank you for saving Japanese children!!

Chair:Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

5:10 PM - 5:40 PM Track6 (現地会場)

#### [ISPHLT-SE]

### International Symposium of Pediatric Heart and Lung Transplantation

#### Lunch Seminar 1

#### 劇症型心筋炎に対する Impella補助循環用ポンプカテーテル

Chair:安河内 聡 (相澤病院臨床検査センター)  
12:00 PM - 12:50 PM Track6 (現地会場)

#### [ISPHLT-LS1]

○戸田 宏一 (大阪大学医学部附属病院)

### International Symposium of Pediatric Heart and Lung Transplantation

#### Oral Session 1

#### Pediatric heart treatment

Chair:Kenichi Kurosaki (Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)  
11:10 AM - 11:45 AM Track6 (現地会場)

#### [ISPHLT-OS1-1] Reversible cerebral vasoconstriction syndrome after pediatric heart transplantation

○Hidekazu Ishida, Jun Narita, Ryo Ishii, Masaki Hirose, Kazuhisa Hashimoto, Keiichi

Ozono (Department of Pediatrics, Osaka  
University Graduate School of Medicine,  
Japan)

[ISPHLT-OS1-2]

○Takahiro Shindo (Division of Cardiology,  
National Center for Child Health and  
Development, Japan)

International Symposium of Pediatric Heart and Lung Transplantation

## Chair Lecture

### Struggle to save children with end-stage heart failure

Chair: Soichiro Kitamura (Japan Cardiovascular Research Foundation / National Cerebral and Cardiovascular Center, Japan)

Fri. Jul 9, 2021 1:00 PM - 1:35 PM Track6 (現地会場)

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#### [ISPHLT-CP] Struggle to save children with end-stage heart failure

○ Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

(Fri. Jul 9, 2021 1:00 PM - 1:35 PM Track6)

## [ISPHLT-CP] Struggle to save children with end-stage heart failure

○Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

After the Bailey's first xeno HTx in 1984, the hundreds of neonates and small infants with end-stage heart failure are living today because of primary or secondary HTx in the world. The number of pediatric HTx has been increasing and their survival has been acceptable in every recipient age. However, pediatric brain-dead organ donation had not been accepted until 2010 in Japan. In 1988, the Japan Medical Association professed that it would accept brain death as human death. In 1990, the Provisional Commission for the Study on Brain Death and Organ Transplantation was set up in 1990. The draft of the Organ Transplantation Act was proposed in 1994. Finally, on October 16, 1997, the Organ Transplant Act took effect, which enabled brain dead organ donation only if the person expressed in writing prior to death his or her intent to agree donate his/her organs. In addition, the Act states that "only persons 15 years and above can express to donate". Then, heart transplants to small children become impossible. So, we started to send children with end-stage heart failure to Dr Bailey as other pediatricians did and continued to perform xeno HTx experiments. But we finished experiments due to FDA and WHO recommendation against pediatric xenotransplantation. Since 2003, the author and members of Japanese Associations of Transplant patients made many efforts to revise the Act and finally the Act was revised in 2010. After then, the number of pediatric HTx has increasing in Japan and finally exceeded that of HTx abroad.

International Symposium of Pediatric Heart and Lung Transplantation

## Keynote Lecture 1

### The world of pediatric heart transplantation from the beginning

Chair: Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

Fri. Jul 9, 2021 9:00 AM - 9:30 AM Track6 (現地会場)

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#### [ISPHLT-KL1] The world of pediatric heart transplantation from the beginning

○Linda J Addonizio<sup>1,2</sup> (1. Pediatric Cardiology, Columbia University Vagelos College of Physicians and Surgeons, USA, 2. Morgan Stanley Children's Hospital, USA)

(Fri. Jul 9, 2021 9:00 AM - 9:30 AM Track6)

## [ISPHLT-KL1] The world of pediatric heart transplantation from the beginning

○Linda J Addonizio<sup>1,2</sup> (1.Pediatric Cardiology, Columbia University Vagelos College of Physicians and Surgeons, USA, 2.Morgan Stanley Children's Hospital, USA)

In pediatrics we have never been able to accept that the death of a child was inevitable. Physicians over the years have tried experimental treatments in order to try to save those children on death's door, and families have been willing participants. For children with congenital heart disease physicians began pushing boundaries in 1938 with ligation of a ductus and in 1944 with creation of a Blalock-Taussig shunt. This was quickly followed by complex intracardiac procedures starting in the 1950's that would save children with even complex congenital heart disease. And so it was that in 1967, just 3 days after Dr Christian Barnard performed the world's first heart transplant in an adult, Dr Adrian Kantrowitz in New York attempted a heart transplant in a dying newborn using a donor from an anencephalic baby. He would never have been able to perform this operation in this day and age. The infant died just 6 hours after the procedure, but the seeds were planted for the rise of pediatric heart transplantation.

However, the world would have to wait longer for heart transplantation to be offered again to small children, until the complex care and immunosuppressive therapy necessary for patients to survive had improved enough such that saving a child's life with transplantation would provide them with a good quality lifestyle and the chance for growing up. We will discuss the pioneers in this field over the past 50 years, and the key moments that have allowed our field to progress to where it is today, that children who undergo heart transplantation can expect to grow up, pursue their dreams and have families of their own.

International Symposium of Pediatric Heart and Lung Transplantation

## Keynote Lecture 2

### Pediatric organ donation in USA

Chair: Juntaro Ashikari (Medical Information Headquarters, Japan Organ Transplant Network, Japan)

Fri. Jul 9, 2021 1:45 PM - 2:15 PM Track6 (現地会場)

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#### [ISPHLT-KL2] Pediatric organ donation in the United States of America

○Thomas A Nakagawa<sup>1,2</sup> (1.Division of Pediatric Critical Care Medicine, Department of Pediatrics, University of Florida College of Medicine. Jacksonville, FL. USA, 2.Carolina Donor Services. Durham, NC. USA)



(Fri. Jul 9, 2021 1:45 PM - 2:15 PM Track6)

## [ISPHLT-KL2] Pediatric organ donation in the United States of America

○Thomas A Nakagawa<sup>1,2</sup> (1.Division of Pediatric Critical Care Medicine, Department of Pediatrics,  
University of Florida College of Medicine. Jacksonville, FL. USA, 2.Carolina Donor Services. Durham, NC.  
USA)

This presentation will discuss the current state and growth of pediatric donation in the United States of America. Information about brain dead and circulatory death donors will be reviewed. Donation data including the number of donors and transplants completed annually will be presented. Growth of DCD donation in children contributing more organs for transplantation will be presented. Advancements in transplant technology that are impacting children will be reviewed.

International Symposium of Pediatric Heart and Lung Transplantation

## Keynote Lecture 3

### Pediatric heart transplantation: from the beginning

Chair: Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

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#### [ISPHLT-KL3] Pediatric heart transplantation: from the beginning

○Joyce K Rusch (Cardiac Transplant, Loma Linda University, USA)

(Fri. Jul 9, 2021 3:20 PM - 3:50 PM Track6)

## [ISPHLT-KL3] Pediatric heart transplantation: from the beginning

○Joyce K Rusch (Cardiac Transplant, Loma Linda University, USA)

Pediatric heart transplantation at Loma Linda University began in 1985 with the transplant of a 4 day old infant born with hypoplastic left heart syndrome. The success of this transplant made it necessary to establish a reliable infant donor identification process to match future potential recipients and donors. It also necessitated designing treatment protocols for the clinical management of infants after transplant. As well, it was necessary to identify dedicated nurse clinicians, so called transplant coordinators, to carefully oversee each step of the transplant process.

The first step in the transplant process begins with the referral of any potential recipient. This first call sets in motion a cascade of activity that gives definition to the transplant coordinator's role as communicator and family advocate. As a first priority, the transplant coordinator facilitates the rapid transfer of information from the transplant center to the referral facility regarding management techniques for the potential recipient while awaiting diagnostic data that supports the need for heart transplantation. Communication with the family may begin at this time. It is important to provide the family with information about their options and the serious, lifelong commitment involved if the choice for transplant is made.

The second important call is the donor call, which necessitates a rapid but thorough assessment of the donor, especially in regard to cardiac function. The transplant coordinator's responsibilities include organizing the pre-operative orders for the recipient, making flight and logistical arrangements for the donor recovery process, including notification of all team members. In the case of Loma Linda, the transplant coordinator accompanies the surgeon on procurement, functioning as a "circulating" nurse in the operating room.

Success in heart transplantation requires a dynamic interdisciplinary team whose members are dedicated to improving the quality of life of the children they serve. The pediatric heart transplant team includes cardiac surgeons, general pediatricians, pediatric cardiologists, neonatologists, immunologists, infectious disease specialists, ethicists and transplant nurse coordinators. At Loma Linda, all primary long-term care is provided by a group of pediatricians, supported by transplant coordinators.

International Symposium of Pediatric Heart and Lung Transplantation

## Symposium 1

### Current status and future aspect of pediatric heart transplantation in the world

Chair: Heima Sakaguchi (Department of Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)

Chair: Shigetoyo Kogaki (Pediatrics and Neonatology, Osaka General Medical Center, Japan)

Fri. Jul 9, 2021 9:40 AM - 11:00 AM Track6 (現地会場)

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#### [ISPHLT-SY1-1] Pediatric heart transplantation in Brazil

○ Estela Azeka (Cardiology, Heart Institute (InCor) University of Sao Paulo Medical School, Brazil)

#### [ISPHLT-SY1-2] Pediatric heart transplantation in Osaka University

○ Jun Narita (Department of Pediatrics, Osaka University Graduate school of Medicine, Japan)

#### [ISPHLT-SY1-3] Pediatric heart transplantation in NCVC

○ Heima Sakaguchi, Norihide Fukushima, Hajime Ichikawa, Takaya Hoashi, Yuki Ito, Hikari Miike, Kenichi Kurosaki, Isao Shiraishi (Department of Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)

#### [ISPHLT-SY1-4] National consultation system of children with end-stage heart failure in Japan

○ Takahiro Shindo (Division of Cardiology, National Center for Child Health and Development, Japan)

(Fri. Jul 9, 2021 9:40 AM - 11:00 AM Track6)

## [ISPHLT-SY1-1] Pediatric heart transplantation in Brazil

○Estela Azeka (Cardiology, Heart Institute (InCor) University of Sao Paulo Medical School, Brazil)

Heart Transplantation has been the treatment of choice for children with complex congenital heart disease and cardiomyopathies refractory to conventional therapy. The first newborn who has underwent to heart transplantation in Brazil was on October 30, 1992. The indications, complications and Kaplan meier curve will be present

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(Fri. Jul 9, 2021 9:40 AM - 11:00 AM Track6)

## [ISPHLT-SY1-2] Pediatric heart transplantation in Osaka University

○Jun Narita (Department of Pediatrics, Osaka University Graduate school of Medicine, Japan)

Activation of a revised Transplant Act open doors to pediatric heart transplantation in Japan, and it passed for 11 years. We experienced 30 cases of domestic pediatric heart transplantation in Osaka University Hospital to date according gradually to increase donor volume. However, pediatric heart transplant recipients need over 2-3 years long waiting time even if now. In addition, pediatric heart transplantation in Japan remain not to perform from June 2020 in combination with impact of COVID-19. Although it is largely good outcomes that overall survival rate after pediatric heart transplantation in our institute is 93%, varied post-transplant complications are found and it is often difficult to have their management and care, and life after heart transplant is the tough road. On other hand, 34 cases of pediatric heart transplantation abroad had followed up in our institute until now, and their overall survival rate was 87%. A possible cause of the difference in survival rates between domestic and abroad is that abroad transplantation has a longer follow-up period than domestic, and serious complications such as post-transplantation lymphoproliferative disorder (PTLD) are transferred to our hospital with department of hematooncology. Now, most of abroad post-transplant patients over 15 years old had transition to adult cardiology, and only cases with prolonged serious complications are continued followed up in the pediatric team. The transition to adult is also one of the major problems in the future. In a wide variety of complications, PTLD is the most frequent complication of all pediatric heart transplants in our hospital, with approximately the same frequency of cellular/antibody-mediated rejection, followed by renal failure. All patients had been having post-transplant infections for granted, then some cases sometimes developed chronic infection needed continuous treatment. We will cover varied of the points including future vision of pediatric heart transplantation and our reports like above in Osaka University in this symposium.

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## [ISPHLT-SY1-3] Pediatric heart transplantation in NCVC

○Heima Sakaguchi, Norihide Fukushima, Hajime Ichikawa, Takaya Hoashi, Yuki Ito, Hikari Miike, Kenichi Kurosaki, Isao Shiraishi (Department of Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)

With the revision of the Organ Transplant Law, the extension of insurance cover to implantable ventricular assist devices and Berlin Heart EXCOR, major changes have been brought to heart transplantation in Japan in the past decade. The insurance coverage to Berlin Heart EXCOR, in particular, has had a major impact on the current state of pediatric heart transplantation in Japan, which requires a long waiting period for a bridge-to-transplant assist device. The number of patients wishing to travel overseas for transplantation has decreased, and the number of patients on the waiting list for heart transplantation in Japan has increased, making us realize that we are approaching a future where Japanese people can be saved by Japanese people. On the other hand, there are still problems that need to be improved. These include chronic heart failure in the patients with congenital heart disease (CHD) long after the surgery and the protein losing enteropathy after Fontan operation. In the CHD patients long after the surgery, restrictive heart failure is common, and how to avoid to increase central venous pressure and multiple organ (especially liver and kidney) damage during the long waiting period for transplant. In the failed Fontan patients, pulmonary circulatory failure, not ventricular dysfunction, is overwhelmingly associated with heart failure. In Failed Fontan cases, not ventricular dysfunction, but pulmonary circulatory failure is overwhelmingly involved in heart failure. Therefore, left ventricular support alone will not improve the condition, and some new approach to improve hemodynamics or modification of waiting status classification will be necessary. It is not so difficult to discuss such medical indications because of the precedents set in Western countries, but we have to discuss the unique problems faced by adults with congenital heart disease (ACHD). There are many ACHD who are separated from society by long hospital visit, hospitalization, and economic problems. I feel that it is also an important issue to further improve the determination of social indication for heart transplantation in such ACHD patients.

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(Fri. Jul 9, 2021 9:40 AM - 11:00 AM Track6)

## [ISPHLT-SY1-4] National consultation system of children with end-stage heart failure in Japan

○Takahiro Shindo (Division of Cardiology, National Center for Child Health and Development, Japan)

International Symposium of Pediatric Heart and Lung Transplantation

## Symposium 2

### Current status of pediatric organ donation in the world

Chair: Juntaro Ashikari (Medical Information Headquarters, Japan Organ Transplant Network, Japan)

Chair: Thomas A. Nakagawa (Division of Pediatric Critical Care Medicine, Department of Pediatrics, University of Florida College of Medicine/Medical Director,

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#### [ISPHLT-SY2-1] Ethical issues in pediatric organ donation

○ Thomas A Nakagawa<sup>1,2</sup> (1.Division of Pediatric Critical Care Medicine, Department of Pediatrics, University of Florida College of Medicine. Jacksonville, FL. USA, 2.Carolina Donor Services. Durham, NC. USA)

#### [ISPHLT-SY2-2] Pediatric organ donation and transplantation in Japan: achievements in the past decade and goals in the next

○ Juntaro Ashikari (Medical Information Headquarters, Japan Organ Transplant Network, Japan)

#### [ISPHLT-SY2-3] Current status of pediatric organ donation in Japan: should organ donation from abused children be prohibited?

○ Takashi Araki (Saitama Medical Center, Saitama Medical University, Japan)

(Fri. Jul 9, 2021 2:30 PM - 3:10 PM Track6)

## [ISPHLT-SY2-1] Ethical issues in pediatric organ donation

○Thomas A Nakagawa<sup>1,2</sup> (1.Division of Pediatric Critical Care Medicine, Department of Pediatrics, University of Florida College of Medicine. Jacksonville, FL. USA, 2.Carolina Donor Services. Durham, NC. USA)

This presentation will discuss ethical issues related to pediatric donation. Specific issues related to determination of neurologic and circulatory death and donor management will be reviewed.

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## [ISPHLT-SY2-2] Pediatric organ donation and transplantation in Japan: achievements in the past decade and goals in the next

○Juntaro Ashikari (Medical Information Headquarters, Japan Organ Transplant Network, Japan)

The Revised Organ Transplant Act enacted in 2010 enabled donation after brain death with consent from the donor's family when the donor did not have a document regarding organ donation such as a donor card, whereas prior to the revision both the donor documentation and the family consent was mandatory. The organ donation documentation is considered legally binding as a will, which in Japan is valid from age 15, therefore before the revision, pediatric patients would not be able to donate their organs after brain death. When the revision of the Act was discussed between the politicians, there was strong resistance claiming that the family may be trying to hide child abuse by donating their organs, so the revised Act included the mandatory exclusion of child abuse cases from organ donation, requiring the donor hospitals to have a manual and a committee for child abuse. The donor hospitals prepared for pediatric organ donation were 293 among the 914 emergency medical hospitals (32.0%) as of 2019. At the Japan Organ Transplant Network have been providing training workshop programs for pediatric donor hospitals offline and recently online, and also offering support programs to help pediatric donor hospitals develop their own organ donation manual and hold organ donor training simulations within their own facility. The recipient selection criteria, which is determined by the Ministry of Health, Labor and Welfare, prioritized pediatric hearts to be transplanted to pediatric patients since 2010, but kidneys, liver, pancreas and lungs were similarly prioritized recently between 2018 and 2020. In 2019, there were 18 pediatric donors (18.5%) within the 97 donations after brain death, adding up to a total of 52 from the enactment of the revised Act to 2020. From the 52 pediatric donors, 134 pediatric recipients have been transplanted, including 42 heart and 16 lung recipients. Recently we have started a donor hospital inter-cooperation program where pediatric hospitals with knowledge and past experience of pediatric organ donation share and exchange their expertise with other pediatric hospitals, cultivating a positive culture in pediatric organ donation and transplantation for the next decade.

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## [ISPHLT-SY2-3] Current status of pediatric organ donation in Japan: should organ donation from abused children be prohibited?

○Takashi Araki (Saitama Medical Center, Saitama Medical University, Japan)

Although the number of brain-dead organ donations from pediatric patients has gradually increased since the enactment of the revised law, the actual number in Japan is still far below that of developed countries. Our research so far has revealed the following multifaceted issues: the process of confirming the will of children and their families to donate their organs, measures to exclude abuse, and care for the grieving families. We published a textbook on pediatric organ donation under brain death (to be published in July 2021), a proposal for a process to exclude abused children, a support system for patients' families, and many other results of the "Development of an educational program that contributes to the development of a system necessary for organ donation from children" in the Research Project for Infrastructure Development of Transplantation Medicine from FY2018 to FY2020. We will continue this research team system. We will continue this research team structure and further promote the above research, especially with the cooperation of pediatric societies.

In the Japanese system, organ donation from abused children is prohibited. As a result, when a patient becomes critically ill and reaches the end of life, it is necessary to deal with the family with a high level of care on the one hand, and on the other hand, to confirm whether there was any involvement of abuse in the child's injury, and to investigate the history of abuse in the past. While there are strong critics of this system, there are also those who believe that organ donation needs to be discouraged from the perspective of case investigation. In Japan, where there is no medical examiner, a bizarre barrier of exclusion from abuse stands in the way of children and their families who wish to donate their organs under brain death. Are abused children ineligible for organ donation? Should abused children be excluded? We would like to discuss these issues, including ethical considerations, while listening to the opinions of participants from overseas.

International Symposium of Pediatric Heart and Lung Transplantation

## Symposium 3

### How to manage pediatric thoracic organ transplant recipient

Chair:Fumiko Mato (Center for Pediatric Diseases, Osaka University Hospital, Japan)

Chair:Yumiko Hori (Department of Transplantation, Department of Nursing, National Cerebral and Cardiovascular Center, Japan)

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[ISPHLT-SY3-1] The role of the child life specialist in the USA and Japan: the creation of a beautiful friendship

○Alison Heffer (Child Life Department, New York-Presbyterian Morgan Stanley Children's Hospital, USA)

[ISPHLT-SY3-2] The role of recipient transplant coordinator in pediatric heart transplantation in Japan

○Yumiko Hori<sup>1,2</sup>, Nobuaki Konishi<sup>1,2</sup>, Ayaka Arizono<sup>1,2</sup>, Heima Sakaguchi<sup>3</sup>, Norihide Fukushima<sup>2</sup> (1.Department of Nursing, National Cerebral and Cardiovascular Center, Japan, 2.Department of Transplantation, National Cerebral and Cardiovascular Center, Japan, 3.Department of Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)

[ISPHLT-SY3-3] The role of child life specialists in pediatric heart transplantation in Japan: bridging the gap, serving as a buffer, and offering scaffoldings

○Fumiko Mato (Center for Pediatric Diseases, Osaka University Hospital, Japan)

(Fri. Jul 9, 2021 4:00 PM - 4:55 PM Track6)

## [ISPHLT-SY3-1] The role of the child life specialist in the USA and Japan: the creation of a beautiful friendship

○Alison Heffer (Child Life Department, New York-Presbyterian Morgan Stanley Children's Hospital, USA)

In 2001 Morgan Stanley Children's Hospital began performing heart transplants on patients who came to the United States from Japan. Since 2001 we have transplant more than 20 patients. As a child life specialist I have been a member of the multidisciplinary that has provided care to these patients when they have come abroad for transplantation. Child Life Specialists are trained professionals who help infants, youth, children and families cope with the stress and uncertainty of illness, injury and treatment. Child Life Specialists can be found both in free standing childrens hospitals as well as those that have pediatric wings within adult hospitals. This presentation will focus on how child life specialist in the United States worked with the child life specialists in Japan to provide continuity of care for the patients coming to the USA for transplantation. The presentation will outline the steps that both child life teams took from the moment that the medical teams confirmed that transplantation was happening. It will outline some tangible steps that medical and psychosocial teams can take to help patients cope with transferring to new facilities.

It is the hope that when the audience leaves this presentation they will understand how child life specialists both in their native country as well as abroad can help make hospitalization as least stressful as possible for both the medical teams and the families benefiting from the services being provided.

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## [ISPHLT-SY3-2] The role of recipient transplant coordinator in pediatric heart transplantation in Japan

○Yumiko Hori<sup>1,2</sup>, Nobuaki Konishi<sup>1,2</sup>, Ayaka Arizono<sup>1,2</sup>, Heima Sakaguchi<sup>3</sup>, Norihide Fukushima<sup>2</sup>

(1.Department of Nursing, National Cerebral and Cardiovascular Center, Japan, 2.Department of Transplantation, National Cerebral and Cardiovascular Center, Japan, 3.Department of Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)

Since the revised Organ Transplant Act which allowed pediatric deceased organ was amended in 2010 EXCOR reimbursed in 2015, allowed small children to wait for much longer period for heart transplant (HTx) and HVAD and HeartMate3 reimbursed in 2019 made larger children wait longer and live at home. Prior to listing, the recipient transplant coordinators (RTCs) are responsible for (1) supporting the decision-making of the parents and the affected child, (2) building a patient support system, (3) understanding the child's daily living conditions before and after HTx, including medication, infection prevention and school life, and the child's adherence to medical treatment, (4) evaluating financial aspects, and (5) motivating patient and family education. During the waiting period, parents and the affected child will be educated on (1) what to expect after HTx and (2) how to make the educated content a habit of daily life. RTCs also support schooling in children with an implantable ventricular assist device (i-VAD) After HTx, support for school attendance and parents and child education will be continued so that the child can become independent and enjoy their school life. Although we provide visiting school service for the school-age children with EXCOR, it is difficult for some of them to

express their thoughts to others or to accommodate their self to others and they often use hurtful words, because they cannot take school education together with other children. It is not so easy for i-VAD children to get used to their body image changes, hospitalization and long absence from the school attended previously by their transferring to Osaka. The RTCs are always working together with physicians, nurses, child life specialists, nursery staffs, and psychologists to address these issues on an individual basis. RTCs should have individualized measures for each affected child, as the waiting period is extremely prolonged due to pediatric organ donor shortage. It is important for RTCs to make the child and parents ready to live during waiting and after HTx, and to support the children to lead a post-HTx self-sustaining social life according to their mental and physical growth.

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(Fri. Jul 9, 2021 4:00 PM - 4:55 PM Track6)

## [ISPHLT-SY3-3] The role of child life specialists in pediatric heart transplantation in Japan: bridging the gap, serving as a buffer, and offering scaffoldings

○Fumiko Mato (Center for Pediatric Diseases, Osaka University Hospital, Japan)

The revised Japanese Organ Transplant Law took effect in 2010; the pediatric heart transplant team was formed at Osaka University Hospital. Since then, in multidisciplinary collaboration to build the foundation of child- and family-centered care, the Child Life Program for pediatric heart transplant recipients and their families has been developed through the process of creating individualized stepwise plans meeting the unique needs of each child and family while organizing basic guidelines responding to their common needs.

Children and families confront a variety of transplant-specific psychosocial issues in pre-, peri-, and post-transplant phases: uncertainty and unpredictability during extended waiting period, isolation and separation associated with relocation and hospitalization, struggle for control due to restriction on activities, lack of autonomy caused by enforced dependence, concerns about prognosis, fear of life-changing complications, threat to future competence, and identity confusion. In addition to those long-term healthcare needs and hurdles, they potentially need to cope with ethical dilemmas and emotional ambivalence: hopefully waiting for transplant and feeling guilty about waiting for donation.

Child Life Specialists, applying therapeutic values of play as a primary modality in developmentally supportive and psychologically appropriate ways, strive to prevent, minimize, and reduce the adverse effects of potentially stressful or traumatic experiences. Empowering children and families to validate their oscillated, incompatible feelings, Child Life promotes their understanding and coping skills and strategies throughout their transplant journey. Child Life interventions, which involve resilience-focused and relationship-oriented approaches, include therapeutic play, psychological preparation, non-pharmacological approaches to anxiety/stress/pain management, peer-to-peer connection, parental involvement, and sibling support. Those interventions are designed to facilitate positive coping with healthcare encounters.

Introducing the examples of Child Life interventions: 1) meaning-making interventions that incorporate story-based process, and 2) legacy-building activities to validate and celebrate medical, developmental, and psychological milestones, this presentation will address how Child Life helps children cope with psychosocial challenges specific to heart transplantation. The primary focus will be on how children can actively participate in their transplant process when being empowered to maintain self-esteem and hope,

enhance a sense of authorship and gratitude, and appreciate the "gift of life" and "life after loss."

International Symposium of Pediatric Heart and Lung Transplantation

## Special Event

### Thank you for saving Japanese children!!

Chair: Norihide Fukushima (Department of Transplant Medicine, National Cerebral and Cardiovascular Center, Japan)

Fri. Jul 9, 2021 5:10 PM - 5:40 PM Track6 (現地会場)

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[ISPHLT-SE]

(Fri. Jul 9, 2021 5:10 PM - 5:40 PM Track6)

[ISPHLT-SE]

International Symposium of Pediatric Heart and Lung Transplantation

## Lunch Seminar 1

### 劇症型心筋炎に対する Impella補助循環用ポンプカテーテル

Chair: 安河内 聡（相澤病院臨床検査センター）

Fri. Jul 9, 2021 12:00 PM - 12:50 PM Track6 (現地会場)

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[ISPHLT-LS1]

○戸田 宏一（大阪大学医学部附属病院）



(Fri. Jul 9, 2021 12:00 PM - 12:50 PM Track6)

## [ISPHLT-LS1]

○戸田 宏一（大阪大学医学部附属病院）

International Symposium of Pediatric Heart and Lung Transplantation

## Oral Session 1

### Pediatric heart treatment

Chair: Kenichi Kurosaki (Pediatric Cardiology, National Cerebral and Cardiovascular Center, Japan)

Fri. Jul 9, 2021 11:10 AM - 11:45 AM Track6 (現地会場)

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#### [ISPHLT-OS1-1] Reversible cerebral vasoconstriction syndrome after pediatric heart transplantation

○Hidekazu Ishida, Jun Narita, Ryo Ishii, Masaki Hirose, Kazuhisa Hashimoto, Keiichi Ozono (Department of Pediatrics, Osaka University Graduate School of Medicine, Japan)

#### [ISPHLT-OS1-2]

○Takahiro Shindo (Division of Cardiology, National Center for Child Health and Development, Japan)

(Fri. Jul 9, 2021 11:10 AM - 11:45 AM Track6)

## [ISPHLT-OS1-1] Reversible cerebral vasoconstriction syndrome after pediatric heart transplantation

○Hidekazu Ishida, Jun Narita, Ryo Ishii, Masaki Hirose, Kazuhisa Hashimoto, Keiichi Ozono (Department of Pediatrics, Osaka University Graduate School of Medicine, Japan)

Neurological complications are an important cause of morbidity and mortality in patients after heart transplantation. Reversible cerebral vasoconstriction syndrome (RCVS) is a rare but increasingly recognized syndrome characterized by diffuse segmental constriction of cerebral arteries with thunderclap headache that can lead to severe neurological complications such as stroke and seizure. Here, we report three cases of RCVS, induced by tacrolimus in adolescent patients (13, 16, 17 years old) after heart transplantation. We demonstrate the characteristic magnetic resonance imaging (MRI) and magnetic resonance angiography (MRA) images in this presentation. All cases have thunderclap headache as the typical clinical symptom. All patients underwent heart transplantation after a long waiting period and developed headache within a month of transplantation. Two of them were implanted ventricular assist device. Diagnosis of RCVS was confirmed by repeated MRI scans. Tacrolimus was suspected as the causal agent in all cases, and the change of the immunosuppressant to cyclosporine and administration of calcium channel blocker were highly effective. We should suspect RCVS and should immediately conduct MRI and MRA even in pediatric patients when they claim thunderclap headache after heart transplantation.

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(Fri. Jul 9, 2021 11:10 AM - 11:45 AM Track6)

## [ISPHLT-OS1-2]

○Takahiro Shindo (Division of Cardiology, National Center for Child Health and Development, Japan)