



Please make "Noa-chan" undergo heart transplant surgery!

"Operation Save Noa": Heart Transplant Surgery for Baby Girl Noa



Official web site

<http://noaonaga.com/>



Donation site

We have set up a crowdfunding account so that overseas supporters can make donation in US Dollars by credit card. Please find donation instructions in below page:

<https://life.indiegogo.com/fundraisers/heart-transplant-surgery-for-noa>

Heart Transplant Surgery for Noa



Noa is a beautiful baby girl who was born on 27 May 2014. She is a daughter of Ryoko and Tsukasa Onaga, who reside in Urasoe City, Okinawa, Japan. Soon after her birth, doctors found something was wrong with Noa's heart. After various checkups, Noa was finally diagnosed to have "dilated cardiomyopathy," which is a progressive form of "non-compaction of the left ventricle". In other words, the left ventricular myocardium (which is the muscular tissue of the heart that contracts to push out blood) is not dense enough, but is more like a soft sponge that does not function properly. Unless she undergoes heart transplant surgery, Noa may not be able to survive much longer.

In March 2015, Noa was in critical condition and had to be flown by an air ambulance the National Cerebral and Cardiovascular Center in Osaka, Japan. On 1 April 2015, Noa had to undergo emergency operation in order to install artificial heart devices. Although the operation was successful, having the artificial heart devices for an extended period of time increases the risk of complications, such as brain infarction (stroke). In order to minimize such risk, Noa needs to get a heart transplant surgery done as soon as practically possible.

Compared to US and Europe, Japan does not have a positive record in organ transplants upon brain death. Since the Organ Transplant Act went into effect in 1997, Japan started to conduct organ transplant upon brain death, but the total operations done in the past 18 years have amounted to only 340 cases, whereas in the US, more than 2,000 heart transplants are said to be carried out every year. Moreover, since donors for organ transplants under the age of 15 has been allowed only since 2010, there aren't many transplant donors in Japan to begin with. Facing this difficult reality at home, infants and children like Noa do not have a choice other than to go overseas to get a heart transplant surgery.

With the close support of doctors at the hospital in Osaka, however, Noa was very lucky to have Columbia University in New York accept her for a heart transplant surgery. However, currently there is no publicly available financial support, including insurance, which can cover the necessary medical expenses for surgery of this magnitude and complexity. In addition to the medical expenses that will be incurred, Noa's parents also need to consider airfare and living costs for the duration of their stay in the US, which would amount to an extraordinary cost that one family will not be able to pay readily.

Meanwhile, Noa has been bravely fighting with her illness every day, waiting patiently for the day when she finally gets her heart transplant surgery done. We, as long-time friends of Noa's parents, decided to set up "Operation Save Noa" and have begun our charity activities to support Noa's family. We are committed to make every possible effort to save the life of this beautiful little girl, and to see the Onaga family live a peaceful life together at home. We would ask for your kindness and support in helping them through donations and/or participation in our activities. Thank you so much for taking your time to visit our site, and for thinking of Noa and her family.

"Operation Save Noa" Co-Partners: Makoto Taira, Yoko Kosuga, Shinkatsu Kise

"Operation Save Noa" executive office (NOA-CHAN WO SUKUU KAI)

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Estimated Cost for Noa's Heart Transplant Surgery Overseas (as of 22 August, 2015)

Breakdown of target estimated cost that needs to be raised : 2.48 million USD (320 million yen)

Deposit to the hospital 1.85million USD

(approx. 238.65million yen @129yen/USD)

Other medical expenses 0.14 million USD (18.85million yen)

Transportation (charter flight, roundtrip airfare, ambulance, etc) 0.43million USD (56million yen)

Living expenses while in US 39,000USD (5million yen)

Administration fee for the NGO 12,000USD (1.5million yen)

Total Estimated Cost 2.48million USD (320 million yen)



Parents greeting

We fondly recall the moment our daughter Noa was born. After 49 long hours of labor, we were finally able to meet with our daughter for the first time. When we held her dearly in our arms, we felt committed that we will do whatever possibly can to save our daughter as long as we live. And we dreamt of the years passing by where our beloved daughter will be nurtured in the beautiful sceneries and kindness of the people of Okinawa.

On the 15th day after her birth, we found out for the first time that something was wrong with Noa. After vomiting a huge amount of milk, Noa was rushed to the hospital, where she was diagnosed to have a very serious heart problem, which is called "left ventricle non-compaction". At that point, Noa had a heart failure and was in a very critical condition.

When we were taken to the ICU, we encountered Noa, who was unconscious, with an artificial respirator and lots of tubes connected to her. She was completely fine until yesterday, so why is this happening to our daughter? We were not able to accept this harsh reality and kept asking ourselves the cause of her illness, which brought us more pain and grief.

While Noa was able to survive through her critical condition and was able to get out of the hospital for a brief period of time, that didn't save her from her illness. On the contrary, Noa's heart continued to worsen day by day.

While we were spending sleepless nights filled with fear and worries, in March 2015, the doctor suggested a possible heart transplant surgery for Noa. Soon after this conversation, on 26 March, Noa was transferred by a doctor helicopter to National Cerebral and Cardiovascular Center in Osaka. Upon arrival at the hospital, Noa had to undergo an emergency operation in order to install artificial heart devices, which was successful.

We found out later that Noa's heart condition was much worse than we had originally imagined, and that she may not have been able to survive a day longer, had it not been for the timely operation. We were struck with a harsh reality that in order for Noa to survive, there was no option left for Noa other than to get a heart organ transplant.

Since April 1, 2015, the National Cerebral and Cardiovascular Center eased the regulation, after which doctors were able to install artificial heart to infants and children in the event of emergency, even without an organ transplant registration. Noa was very blessed in that she was the very first case that was allowed to have an artificial heart installed after the deregulation went into effect. With lots of luck and close support from the hospital, Noa was able to win a little more time, until she gets a heart transplant.

However, while in the hospital, Noa had a major cerebral hemorrhage attack and had to undergo brain surgery. In order to avoid thrombus, or blood clots in the brain, we found out that the pumps for the artificial heart need to be regularly replaced. To our dismay, we had to face the harsh reality that Noa's life continues to be in danger.

We are so proud to be the mother and father of Noa, who has survived all the risky events that challenged her life. And we are convinced that through her courage and strong will, Noa continues to send us a message that yes, "I want to live." We are committed to do anything possible to save our beautiful daughter. It is our strong and earnest wish that Noa gets a heart transplant surgery done as soon as practically possible.

Since Japan's Organ Transplant Act was revised in 2010, transplants for infant and children are now possible; however, as of end August 2015, there have only been 3 cases of organ transplants to children below 6 years old, and we do not expect this record to improve in the near timeframe.

Under such circumstance, with the support of doctors at the hospital in Osaka, Noa was very lucky to have Columbia University in New York accept her for a heart transplant surgery. However, currently there is no publicly available financial support which can cover necessary expenses for an organ transplant surgery overseas. The estimated cost that will be incurred would amount to a fortune that one family will not be able to pay readily. We would therefore ask for close support of all of you in Okinawa, Japan and overseas to help us achieve this goal.

We thank you so much for taking your time to read this, and to think of Noa and our family.
We are dreaming of the day when our family can live peacefully together in Okinawa.
We really appreciate your kindness and support in advance!

Tsukasa Onaga (dad)
Ryoko Onaga (mom)
...and the love of our life, Noa