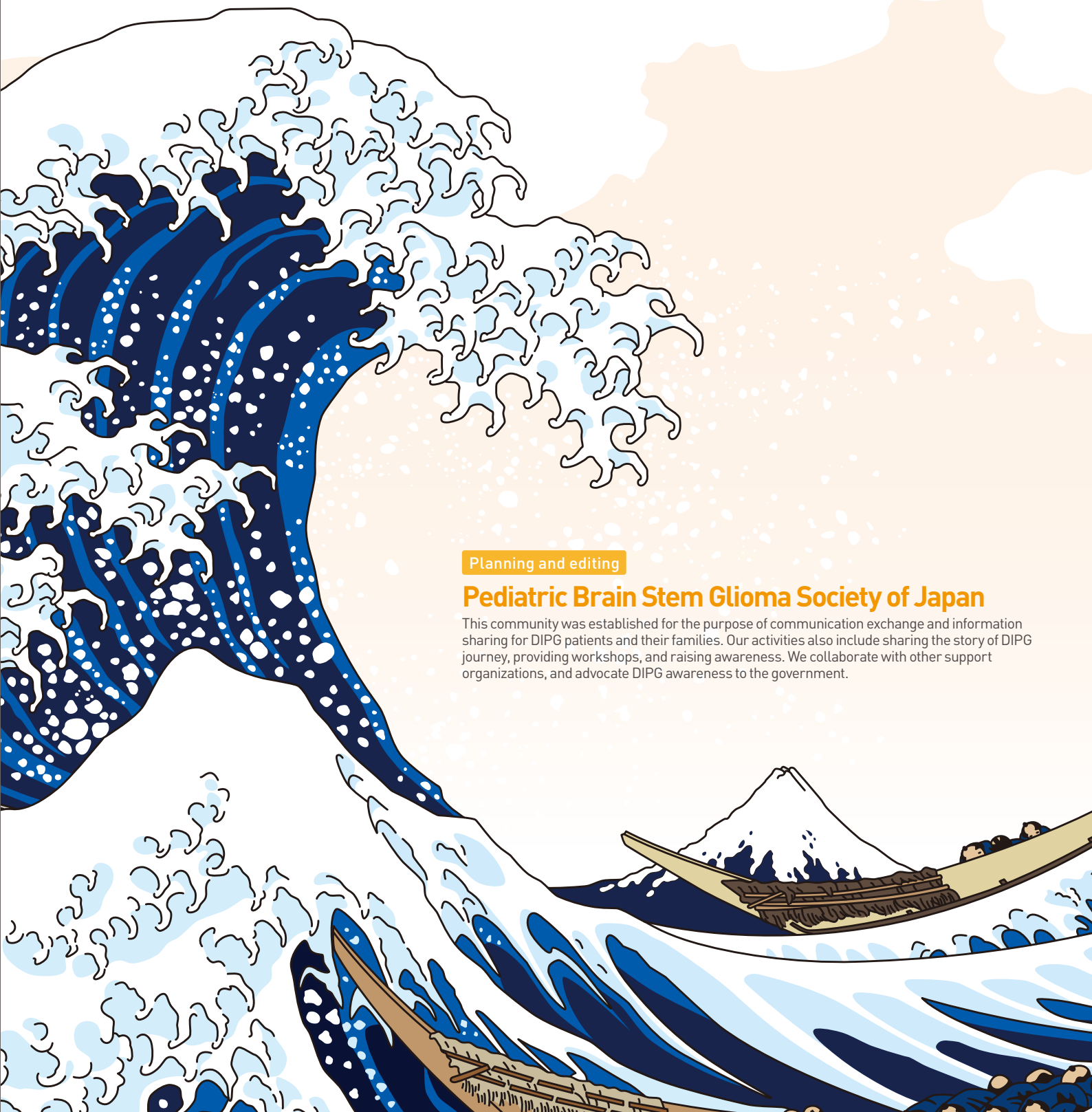
DIPG patients, their families, and support in Japan



Planning and editing

Pediatric Brain Stem Glioma Society of Japan

This community was established for the purpose of communication exchange and information sharing for DIPG patients and their families. Our activities also include sharing the story of DIPG journey, providing workshops, and raising awareness. We collaborate with other support organizations, and advocate DIPG awareness to the government.

Save Our Children Together: Many children were lost due to DIPG. Children need an effective treatment as soon as possible. Let's develop multi-national clinical trials in Japan.

table of contents

Haruka's Journey

Basic Data

Residence	Kawasaki City, Kanagawa, Japan
Parent, Autho	Author: Hisato Tagawa
Child	Haruka Tagawa
Date of birth	June 7, 1991
Age of onset	6 years old
Year of onset	August 1997
Year of death	February 1998

Haruka gave me the message that children with DIPG or other illnesses need a quality of life which allows them to enjoy childhood. She taught me the importance of being a child in the hospital while she was on treatment.

I told my daughter, Haruka, that there was a lump inside her head and would therefore require hospitalization to make the lump smaller with a laser beam (radiation therapy). At the time, I was in shock and confused as the doctor shared that Haruka had only 6 months to live. I was told there was no cure and to prepare for the worst. Despite this prognosis, I was hopeful and endlessly searching for a cure to treat Haruka's disease. I bought a child-friendly supplement and mixed it in her food. Her legs and arms were paralyzed so I arranged massage therapy for her. During radiation therapy, Haruka was hospitalized from September until the end of October. She was able to spend time with us at home after the radiation therapy. While we were on vacation, she was hospitalized due to a headache. By late evening, Haruka was no longer able to breathe on her own and required life support. On February 15th, it was determined that Haruka was brain dead, and subsequently, she was removed from life support.

DIPG is a rare type of cancer that forms in a child's brainstem. It's an incurable tumor that grows fast. I would like to see children's rights respected, not only regarding medical treatment but their rights to be a child. The family should be protected from isolation in the community due to DIPG. I would like people to understand the importance of children's hospice and create awareness in society.

Haruka gave me the message that children with DIPG or other illnesses need a quality of life which allows them to enjoy childhood. She taught me the importance of being a child in the hospital while she was on treatment. I started to improve the medical environment for children. Haruka's message gave me the power to strive.

Since 2023, I raised money to build the house, Lila, that provides a place for families to stay together while being in close proximity to the children's medical center in Yokohama City. Also, I was able to open a children's hospice - "Umi To Sora No Ouchi" in Yokohama city with the donations from the nurse who passed away and wanted to support children's hospice.

There is not much support for children with cancer in Japan, aside from the medical cost being free. There is no support for siblings or parents, and families are isolated. Due to Haruka's cancer journey, I have learned the importance of family support and also quality of time with children. The idea for children's hospice is spreading from England to all over the world and I am hoping that I can spread awareness for children's hospice in Japan.

I think the family who lost children with DIPG overcome sadness and realize the importance of pharmaceutical development. I believe we are all empowering everyone to help cure childhood cancer and support children and family.

Yudai's journey

Basic Data

Residence	Tomiya City, Miyagi, Japan
Parent, Autho	Yuri Chiba
Child	Yudai Chiba
Date of birth	April 9, 2014
Age of onset	8 years
Year of onset	May 2021
Year of death	July 2022

Our life was changed when the doctor gave us the news no parent shouldever have to hear: "There is no effective treatment, and his life expectancy is about a year. There isn't much time left and please cherish the time he has."

In May 2021, our 8-year-old son, Yudai, was diagnosed with a brain tumor. He just started elementary school at the time. After few weeks of blurry visions and walking issues, our pediatrician sent him for a test. Our life was changed when the doctor gave us the news no parent should ever have to hear: "There is no effective treatment, and his life expectancy is about a year. There isn't much time left and please cherish the time he has."

He was given a year to live due to brain stem glioma.

Yudai was hospitalized and underwent radiation therapy for 2 and half month. After the discharge, he developed hydrocephalus and had a shunt placement. There was no change in the size of his tumor after radiation therapy. About 4 months after radiation therapy was completed, MRI scans showed evidence of tumor shrinkage. However, another scan 6 months later showed that his tumor had grown again.

We were hopeful to find a miraculous treatment for Yudai, despite knowing that there was no real cure for eradicating his tumour.

We also wanted to focus on spending quality time with him and ensuring that we could preserve as much normalcy in his life that could be allowed. We registered him at school and discussed ways to keep him in the classroom. We arranged dinner parties with our family friends. We tried to create as many positive memories as possible with Yudai to cherish what time he had left.

Yudai tragically passed away on July 17th. July 17th was also his brother's 4th birthday. I believe Yudai chose this day to leave us because he was very kind and wanted to ensure that the day he passed would not be enshrined in sadness.

After Yudai passed away, we established a support group for pediatric cancer. There were no support groups or grief care where we resided. We felt abandoned by society due to isolation, sadness, and frustration. There was no contingency plan for the family and children.

We do not want people to feel the same way as we did. That is why we started a support group with his grieving siblings in order for us to support family and children who have experienced the trauma of losing a loved one. Based on our experience, we have requested to improve the hospital system. We started supporting family and children facing this disease. We also started raising awareness for childhood cancer treatment.

We want to do whatever we can for other families and children. We know how research and advances in treatment can impact children and improve their quality of life.

Iroha's Journey

Why Iroha? Why not me? I always wonder why it was her.

Basic Data

Residence	Uruma City, Okinawa, Japan
Parent, Autho	Ran Ogawa
Child	Iroha Ogawa
Date of birth	March 18, 2011
Age of onset	10 years
Year of onset	September 2021
Year of death	March 2022

My daughter, Iroha, passed away a week before her 11th birthday. Iroha was diagnosed with DIPG. DIPG is a very lethal disease with a very low survival rate once diagnosed, averaging 8-11 months from diagnosis. This diagnosis has tremendous impacts on families having to come to terms with a diagnosis that has a prognosis of a swift deterioration. To give perspective, imagine going to a doctor to discuss a new onset of symptoms where they respond, “Your daughter has only 6 months to live- no cure, nothing whatsoever.” This was a reality for Iroha and her family as they watched helplessly as the disease manifested in Iroha. Everything was taken away from her as a human because of this disease.

I used to worry and wonder about her future; “What kind of career would she pursue as an adult? What kind of talents would she have? Would she marry a good man? What kind of life would she have lived?” These are all questions that will never be answered since she is gone now.

DIPG gave her the worst and most cruel experience.

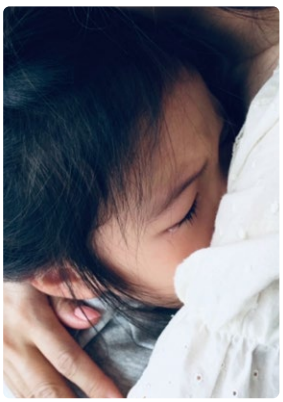
While her friends were able to play and run around, she gradually lost the ability to move her body. Iroha was left behind, isolated, anxious, and the fear spread inside. Consequently, there was nothing she could do about it. She had no choice but to accept her fate- a fate that not even a grown adult could conceptualize nor fathom.

“I didn't really understand what the doctor was saying.” I still remember her words when Iroha told me this when she had discovered her illness. She must have been so scared at the time. She pretended not to understand what the doctor said because she did not want me to worry about her.

Iroha’s cancer journey

Iroha underwent radiation therapy for a month. At the time, there were no concerns when she finished all treatment. However, she became worse within a month or two, and her condition continued to worsen. The DIPG rapidly progressed beyond our expectations. Every week it seemed as if her dignity as a person was being taken away one by one. She used to walk, but soon required a wheelchair for mobility. She was not able to stand up. Her right hand was paralyzed. She was immobilized. She was bedridden. She lost her speech ability. She used to be a very active girl, but she became weaker and weaker as the days progressed.

Iroha was a fighter. She used her left hand to do her homework with a pencil although her right hand was paralyzed. She got frustrated and cried when she was not able to stand up or walk properly. In the end, Iroha was in so much pain that all she could do was nod her head. I still remember her vividly.



Why Iroha? Why not me? I always wonder why it was her.

I know pharmacologists or researchers may read Iroha’s story. What I want you to know that children with DIPG have no time. Each week becomes increasingly painful for those diagnosed with DIPG. They don’t know which one of their faculties will be impacted next as the weeks progress. They can only anticipate a slow deterioration, questioning when they won’t be able to move their hands or if they may be bedridden tomorrow. This should not be a reality for our children. These children do not deserve this fate- our only hope is finding a cure.

On behalf of children with DIPG, I would like to ask everybody please give them hope and support.
I know my daughter will be smiling happily in heaven saying, "Good Job” when we find a cure for DIPG. I dream that day will come soon so other children and their families do not suffer the same end as Iroha.

Greetings from Pediatric Brain Stem Glioma Society of Japan

DIPG Patients In Japan:
While here are estimations of 1,000,000 new cancer cases each year in Japan, 2500 of these cares are childhood cancer cases. Due to the low incidence and ratio of childhood cancer, it is considered a rare disease. Awareness of the seriousness of DIPG is limited because fewer than 40 to 70 patients are diagnosed with DIPG each year.

DIPG Support Group:
Since 2010, due to the internet awareness of DIPG was recognised. Social media created a safe space for the DIPG community, including children and families. It allowed for the connection of small grass-roots communities to share activities that promoted awareness (community resources, treatment, and hospitals etc.) between patients and families, providing peer support or grief care, signing petitions, advocating for the government, donating gifts, and encouraging fundraisers.

Clinical research of DIPG in Japan is still underdeveloped. Our hope is to find a cure, spread awareness and promote a fundraiser for DIPG.

Health Insurance System and DIPG Research:
Japan has a national health insurance system. Through insurance, basic cancer treatments are provided for free or at a fraction of the total cost. Japanese government also provide research funding to cancer research institutes, therefore, the support groups in Japan have never thought about a medical research fundraiser. Even the biggest support group, Children's Cancer Association of Japan invest a small amount of money for clinical research. Recently, there have been many medications developed for rare diseases in North America. Due to the Japanese medical regulations, the approval process is so complicated. A time lag in accessing new anti-cancer drugs became an obvious issue. It takes a while for anti-cancer drugs to be available and accessible in public. The issue of drug lag became more problematic for childhood cancer because DIPG has a poor prognosis that requires rapid treatment.

Cure For DIPG Now:
We want to promote policies that encourage the Japanese government to support more pharmaceutical companies to research and develop drugs for rare cancers with Japanese pharmaceutical companies. We want children to have an opportunity to join "multi-national clinical trials" and try new anti-cancer drugs. We want to see more clinical research/trials of anti-cancer drugs in Japan. We continue to spread awareness, support and understanding towards childhood cancer research. We continue to promote fundraisers and support for the treatment of childhood cancer. The Pediatric Brain Stem Glioma Society of Japan is committed to support and promote clinical research for DIPG in order for them to find a cure.

DIPG Supporter's Symposium - Our Lemonade Stand Story

In attendance: Takao Nukui (Pediatric Brain Stem Glioma Society of Japan), Nobuyuki Takaki (Torukokikyo Association), Emiko Jinmon (Marucoco club), Miho Terui (HiStar'Snow☆Tsukuba),
Yuri Chiba (Himawari Smile Project), Yumiko Minami (Lemonade Stand 55 in Nagoya),
and Kazumi Shinike (Kurashiki Lemonade Stand – Moka Lemon)

In 2000, Alex who was diagnosed with cancer lead to opening lemonade stand to raise money to help find a cure for all children with cancer. Alex's lemonade stand moved across Japan and her lemonade stand has evolved into a fundraising movement in Japan. This is our Lemonade stand story to share with you today.

Takao: My name is Takao Nukui. I lost my 6 years old daughter, Karen about 13 years ago. I started by creating the support community for children and families affected by DIPG via Internet. Since then, I saw many families and children fighting the illness of DIPG. Many parents lost their children to the disease of DIPG. I believe more than 500 children passed away because of this cruel disease. Despite the battle with cancer, I noticed many families continue or joined to support the cause. Today, seven families gathered to discuss their experience with DIPG. I hope by sharing their activities will see more supports for children and families. I would like to introduce Mr. Takagi who worked with me over 10 years after we lost our children to DIPG.

Surprise, the lemonade stand opened the door to supporting DIPG research in Japan!

Nobuyuki: My name is Nobuyuki Takaki. I lost my first-born daughter while she was Grade 6 in 2013. While my daughter Yuina was in the treatment, I have noticed accessing supports was so complicated, for example children's insurance, increase of research funding, approval for children with disabilities program etc. I started the petition to improve the current system to support children with DIPG. As a result, I was able to raise 23,000 petitions. I was able to meet with the Minister of Health, Labor and Welfare to submit the petition. With the collaboration of professionals and families, I also conducted the DIPG symposiums in 2017 and 2018 for us to solve the issues we face with DIPG. I established support organizations for children who are affected by a childhood cancer, these organizations include children's advocates, hospitals, schools, child life services, and employment supports.

Miho: My name is Miho Terui. I live in Ibaraki prefecture, Japan. My 2-year-old son, Yoshitaka was diagnosed with DIPG. I learned Alex's lemonade stand raised money for the childhood cancer research when I was in despair… his doctor told me that Yoshitaka would not celebrate his 3rd birthday. Yoshitaka was not able to make it but one day, we may find a cure and there will be no more families or children suffering the same pain I had. This is the start for me in setting up a lemonade stand. After Yoshitaka passed away, I continue to work on support organizations with two other grieving families.

Emiko: My name is Emiko Jinmon. In July 2020, I lost my 5-year-old daughter Cocona because of DIPG. I still can't forget what the doctor said, "she can live only for another year" and "there is no cure." My daughter was a trooper, but she passed away after a year of fighting with a brain tumor. I used social media to share my daughter's cancer journey. I met other families and children through social media. I still communicate with them after my daughter's passing.

Kazumi: My name is Kazumi Shinike. I live in Okayama prefecture. In December 2020, I lost my daughter because of DIPG. At the time my daughter was 10 years old. Her name is Moka. She liked to please people and do art crafts. Moka started with a vision problem, and at the time there was no signs of DIPG. Moka started getting crossed eyed when she was in grade 2. The tumor came back when she was in grade 4. She had radiation therapy twice but that did not help her at all. In December 2020, Moka passed away. It has been 2 years since her passing when Emiko asked me to join a lemonade stand cause. Now I am looking at expanding the support activities through an official DIPG organization. I feel children and family deserve to receive supports they need but the services available depends on the area where they reside. I think it is important to raise awareness on the supports children and family require the most.

Yumiko: My name is Yumiko Minami. In August 2017, I lost my 7.5 year old son Fuga to DIPG. Fuga was very kind and loved his family. He was so brave during the treatment. I started to join the lemonade stand to spread awareness and support. I would like to support childhood cancer families especially the families in general.

Yuri: My name is Yuri Chiba and I live in Miyagi prefecture. In July 2022, I lost my son, Yudai when he was in grade 2. I felt abandoned by society as there was no support system during the treatment in my area. After my son's passing, I decided to establish the support organization with Yudai's siblings as I did not want families to feel the same way as I felt during his treatment. Currently, we set up the lemonade stand to support family and children with childhood cancer and provide care to grieving families. I hope to bridge the gap and find a way to support families with supports that I wish I had when I needed supports.

Takao: Thank you for sharing your stories. Emiko, would you please tell us about your lemonade stand? That was the first time I started working with you at the lemonade stand.

Emiko: Our organization was “Lemonade Stand to Spread DIPG awareness in Japan”. Last year, there were 8 organizations participated in this lemonade stand throughout Japan. The reason we started the lemonade stand was, Yumiko contacted me via SNS and said, “Let’s do something together.” Around that time, grieving families had contacted me throughout Japan, and I just thought to ask everyone to join in setting up lemonade stands to raise awareness. The purpose for this lemonade stand is to fund clinical research in this field. I wanted to connect with grieving families in Japan, and I wanted to cheer up grieving families. We decided to set up lemonade stands in June 2020 when we had a first online meeting in April. We started from a place where we had no idea what to do, for example “where should we find a place to set up lemonade stands?”, “Is lemonade homemade?”, “Should it be in a bottle?” and “Where should we buy the lemonade?” We had worries but we were very determined to set up lemonade stands. We made a group via SNS. We reported to each other as lemonade stands were getting prepared. The reason we were able to accomplish this lemonade stand to spread awareness was because of our children. They were the heroes fighting with DIPG. We saw their journeys with DIPG and this is why we were able to start lemonade stands in Japan.

Kazumi: You are right. It was not an easy road for me to join the lemonade stands. I was so afraid of watching the internet after my daughter’s passing therefore, I learned this activity a few years later. I was very encouraged by what the lemonade stands stood for as I thought about my daughter who had passed away the year before. I started sharing my daughter’s information via SNS. People started contacting me because their children were battling cancer. They asked me about my daughter and cheered me on. I started thinking how I can support others. It’s been over three years since her passing, I felt I must do something, and Emiko asked me to join in on the lemonade stands initiative. It was my first lemonade stand. I was very anxious whether I can do this, or if people would support the lemonade stand. My worries were gone when the lemonade stand started. The festival organizer was willing to give us a space to set up lemonade stands, many children and adults came to visit our lemonade stands, including kindergartens, people who lost children with childhood cancers. Many different people came to visit the lemonade stands.

Yuri:I set up lemonade stands in Miyagi prefecture. I still remember many people came to visit us and it was very successful. I continued to experience sadness, anger, and despair in my mind after my child was diagnosed with DIPG. My son Yudai tried his best to live. I wanted people to know Yudai’s life was valued and important. This motivated me to continue with the lemonade stands. However, I feel helpless when I heard children were still dying because of DIPG, and there is no clinical trial in Japan due to the rare disease. I knew I must do what I could to support the cause. My son Yudai, and other children and families with DIPG inspired me to continue the lemonade stands.

Yumiko: This was my first time starting the lemonade stand. This event was successful because of the support and collaboration with others. My work is in the restaurant industry, they were supportive by selling lemonades at their store. I was able to speak to a lot of people at the lemonade stand. Also, the local TV station came and interviewed me. I am glad more people know about childhood cancers and DIPG.

Miho: It was my 30th time attending lemonade stands. I learned about lemonade stands about 3 years ago. This was after I learned about my 2 years old son Yoshitaka’s (AKA Yo-chan) diagnosis. Proton therapy was recommended but it was not effective. His doctor told us “To spend time with him as much as you can.” In May, I decided to discharge him from hospital so Yo-chan can spend time at home. Although his condition was not great, it was miracle that he was able to recover while spending time with his favorite brother. After 6 months of discharge from the hospital, he was able to go out. I decided to take Yo-chan to lemonade stands for the first time. However, one week later, Yo-chan was hospitalized again. It has been 3 years since Yo-chan passed away, but I continue attending and supporting the lemonade stands to raise awareness. I still remember I was able to set up the lemonade stand with Yo-chan. This memory motivates me to live in this world. Going forward, I continue to raise money for children and family so that they can have a hope.

Emiko:I know how you feel. Miho said “I wanted to do lemonade stand with Yo-chan.”

Nobuyuki:I also know how you feel. I also started petitions while my daughter was in treatment. It was my first time to set up a lemonade stand when Emiko asked me to join. I thought whether I could do this as most people have negative perceptions of lemonade stands or perceive it’s for females and children. Takao and I gathered people to set up the lemonade stands. I was so impressed as so many people donated to the cause.

Takao: Yes, I also discovered different perceptions after I set up a lemonade stand around donations as appose to charities. In Japan, donations are not as common as North America. In general, Japanese people are shy. They may want to donate money, but they also do not want people to think they are hypocrites by donating. On the other hand, lemonade stand is a charity business, so people do not have to worry about negative feelings towards donation. That is why a lot of people support us without worries when they view it as charity when we set up lemonade stands. Also, I felt that this helped parents to grieve and support each other through this activity.

Emiko: As a result, we sold 2,978 lemonades during a 2-day event last year. The donation was 822,458 yen ($5,400). We were able to donate the money to childhood cancer research institutes. We also received a gratitude from them. Yumiko was interviewed by 16 local medias. I think a lot of people are aware of DIPG now. It was very successful.

Nobuyuki: Let’s continue lemonade stands going forward. I see some people collaborate with sport teams to spread more awareness.

Yuri: That is right. My organization set up the lemonade stand when there were indoor football games, Nagoya Oceans. My company sponsored Nagoya Oceans and they let me sell the products. I asked them if we can set up lemonade stands, they are fine with it. There are many supporters buying the lemonade every game and there are even more people supporting us now.

Nobuyuki: Wonderful. It is very nice idea to raise awareness effectively about childhood cancer and DIPG through sports activities.

Kazumi: I really want a lot of people to know about this disease. I wonder why there is no cure or treatment for children who has a future.

Takao: I believed there will be a cure after 10 years after the passing my daughter. Unfortunately, the researchers haven’t found a cure yet although research is continually improving. It is not possible to find a cure unless we gather the knowledge and wisdom of mankind.

Yuri:It depends on how we can secure the funding for research.

Emiko: I think so, too. Our organization is not that big yet. It will be difficult for us to raise a big amount of money. It is important for us to raise awareness, telling people about childhood cancer and DIPG, and explaining what DIPG is about.

Takao: Well, we can’t compare between North America and Japan for the donation system or ways of thinking, or about taxes and insurance systems. We hope our government supports the research and clinical trials as we secure funding the research ASAP.

Emiko: For us to set up lemonade stands across Japan is to spread awareness to support clinical research.

The donations we raised are not only spent on clinical research in Japan but also supports organization in North America going forward. I want to continue thinking outside of the box and contribute to finding a cure for DIPG.

Currently, the only treatment option children have is radiation therapy. When tumors came back, there is nothing doctors can do. In Japan, there are limited clinical trials for children with DIPG. There are no other treatment options for children. As parents, it’s cruel to see we can do nothing to support the children. I hope we try our best to continue raising money and spreading awareness and in turn lead to a cure. We will try until we can tell our superheroes good news!

Everybody: Of course!

Takao:Let’s do our best. Thank you so much.

Current Status and Future Perspectives of Drug Lag and Drug Loss in Japan

1 Japanese Pharmaceutical Pricing System and National Health Insurance

Japan has a National Health Insurance system, where the government determines the price of pharmaceuticals covered by insurance. The prices are adjusted annually based on factors such as market wholesale prices, but this system does not necessarily create a competitive market for pharmaceutical companies.

2 Current Status of Drug Lag and Drug Loss and Patients' Demands

Many anti-cancer drugs are developed in Western countries and require regulatory approval for use in Japan. Also, the approval process in Japan is complex, with unique domestic regulations that can hinder pharmaceutical development.
This poses a significant challenge for financially limited overseas emerging biopharmaceutical companies (EBP) entering the Japanese market. The time lag in obtaining approval for drugs already approved in Western countries is a critical issue for patients with rare and pediatric diseases. Patient groups have actively advocated for improvements through signature campaigns and petitions.

3 Patient Group Activities

Patient groups for rare cancers, pediatric cancers, and pediatric brain tumors have actively engaged in various activities, including submitting direct requests to the Ministry of Health, Labour and Welfare through signature campaigns, lobbying in the Diet, and petitioning the government. These efforts led to the establishment of a study group on pharmaceutical regulations within the Ministry of Health, Labour and Welfare in July of last year.

4 Ongoing Regulatory Reform

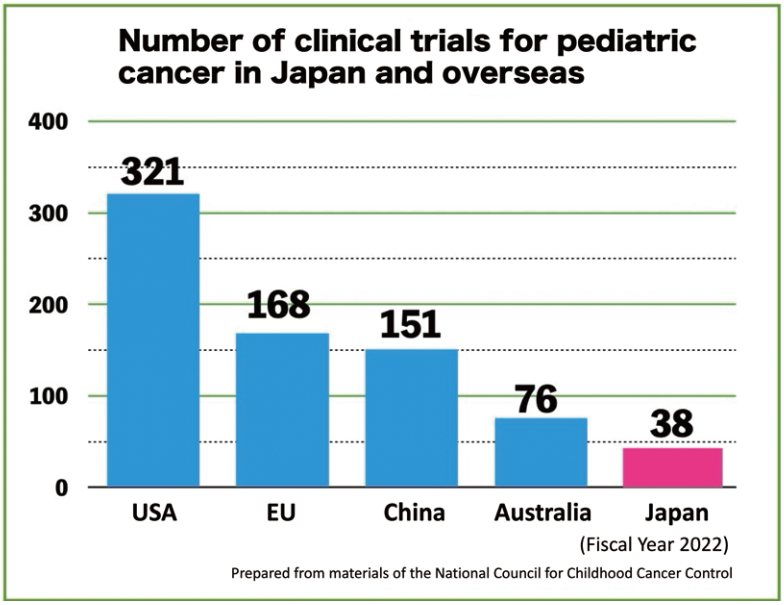
The study group has proposed reforms to pharmaceutical regulations, which are being implemented through notifications from the Ministry of Health, Labour and Welfare. The following are some of the contents of the notifications issued so far:

(A) In principle, waiving the requirement to conduct Phase 1 clinical trials in Japan for international joint clinical trials, if the safety of Japanese participants can be evaluated based on existing data.

(B) In order to reduce drug loss and lag for paediatric medications, joint clinical trial with adult is recommended to introduce an incentive system. As per a pharmaceutical system, it was suggested that the each company can make a decision to develop the joint clinical trial for both adult and children together, create a system that PMDA can confirm the clinical trial, evaluate the research development.

(C) Despite its small number of patients and high medical needs, research development has not progressed sufficiently in Japan. The conditions to promote the system for orphan drugs, they have been revised to (1) clarify the requirements for designation, and (2) accelerate the designation period.

(D) Opened PMDA U.S. office
In Local (business meetings, academic conferences, etc.)
Dissemination of the Japanese Regulator System
·Free consultation on development in Japan
·Consultation possible with English-language materials no translation into Japanese required).



5 Expectations and Future Outlook of Rare Cancer Patients and Families

While the reform of pharmaceutical regulations in Japan has just begun, families of patients with rare cancers, including pediatric brain tumors, strongly hope that the therapeutic drugs being developed around the world will become available in Japan as soon as possible. We also aim to actively participate in international joint clinical trials from Phase 1 and believe that this is the best way to quickly provide children with much needed new drugs.

Message from Pediatric Brain Stem Glioma Society of Japan

Our Hope

We were able to participate in Accelerate from Japan this year because 183 people graciously donated for us to join this forum through crowdfunding. We wanted to learn about DIPG research around the world and to let people know about the situation of DIPG patients in Japan. As it was mentioned in this pamphlet, Japan is very behind in DIPG research when compared to other countries. Every year, many children in Japan pass away from this disease. It may be the same in other countries.We are aware that everybody recognizes there is still a lot of research required to find a cure for this disease.

However, one major difference is that children in Japan are more likely to have relapses after the initial radiation therapy is completed. This means that there is nothing you can do to save the children anymore.

Until recent years, most of the DIPG patients followed the same path no matter which country they resided. But now, we recognised the progress of various clinical trials was through the effort of researchers, research institutes, governments, pharmaceutical companies, as well as the brave patients and their families, and the DIPG support groups.

We have noticed that children with DIPG in foreign countries have the hope of trying clinical trials. Unfortunately, in Japan, there is almost no research on the treatment of DIPG. The children do not have other treatment options, and parents can only sit back and watch their children's disease progress. How painful this is ...

The situation we are facing right now in Japan is the result of not enough effort.

We reflected deeply on this and really hope that we save children with DIPG in Japan. We want to give the children a chance to fight this disease.

We want children to try and join clinical trials such as ONC 201 and GD2 CAR-T therapies. Meeting with everyone at Accelerate is the first step for us. With the hopes of 183 contributors in mind, we promise and strive to establish a better research environment in Japan. We would like to ask everyone around the world to support us in achieving this goal together so children can join these clinical trials.

Pediatric Brain Stem Glioma Society of Japan

Representative	Takao Nukui
web	https://glioma-net.com
mail	gliomanokai@gmail.com
address	957-7 Kamiyasumatsu, Tokorozawa, Saitama, Japan
phone/facsimile	+81 (0)429-96-5068

Japan DIPG Pediatric Brain Stem Glioma Support Network

We will be opening an English page here soon.

web https://soffy-nt.wixsite.com/my-site

Committee members:

Yuri Chiba/Ran Ogawa/Hisato Tagawa/Yuko Moue(RCJ)/Yoshiyuki Majima(RCJ)/
Miho Terui/ Kazumi Shinike/Yumiko Minami/Hiroyuki Kida/Emiko Jinmon/
Nobuyuki Takaki/Noriko Kojima/Yuki Iwakawa/Takao Nukui

Photo by courtesy of :

Rio Kato/Yuno/Mio Sasaki/Hinata Yokosawa/Moka Shinike/Moa Araki/Ema/Yuina Takaki/Cocona/
Fuga Minami/Kosuke Kasuya/Yoshitaka Terui/Towako Kamiya/Saki

Thank you for donating to Accelerate project's crowdfunding campaign.
Thanks to everyone involved in this project and special thanks to Brian Budhoo and Dianne Cheng.