

# Through Their Eyes

CAAMNY RB Foundation Newsletter

Volume I, Issue I, Summer



CAAMNY Mother's Day Celebration p. 10



Find out what upcoming events are around the corner! (p. 5)

Hear from volunteer Mrs. Xiaoqing Ma about her experiences (p. 6)

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The Chinese American Association of Metropolitan New York (CAAMNY) is an IRS-accredited 501(c)(3) non-for-profit organization. The mission of CAAMNY is to promote community awareness and volunteerism, to commit to the education and personal development of Chinese American youth, and to promote Chinese culture and cultural exchange.

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# CAAMNY Executive Team

## Board of Directors

Chair of the Board: *Ying Song*

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Co-chairs: *Lingli Zhang, Wenhua Qi*

## Education Committee:

Co-chairs: *Yun Fan, Xiaoqing Ma*

## Financial and Administration Committee:

Co- chairs: *Xiaomin Bian, Xiaoqing Ma*

## Events and Activities Committee:

Chair: *Ying Song*





# A Letter From the President

**Dear Friends,**

At the opening ceremony of Chinese American Association of Metropolitan New York (CAAMNY) back in February, I shared my personal story of how I got to know the RB families in New York about three years ago, and how I started to devote myself to organizing and providing the much needed volunteer services to these families. During the ceremony I was happy to be approached by many New York parents and children who shared the same passion in charity work and were ready and eager to be involved in these activities. With their advocacy and support, CAAMNY established an RB Children's Foundation and quickly set it in operation. Within a short period of time, we have made significant progress.



To keep the Chinese communities informed and updated of the situation and stories of the RB Children, volunteers designed and printed pamphlets for the RB Children's Foundation, built a website and a WeChat public number for the foundation. CAAMNY also held a workshop by New York private school parents, out of which the ticket income of about \$1000 was all denoted to the RB foundation. With this first fund, we organized a free medical check-up events for the moms of the RB Children. It was a great opportunity for them to direct some of their attention to their own health while devoting all they have for the care of their children.

Many CAAMNY members took part in the "buddy family" activity, where each member partners with an RB family in order to better understand their difficulties and needs and help them in a more personalized and effective way. Many times, volunteers have accompanied the patient families to the clinics and provided them with translation services. On Mother's Day in May, we organized a picnic event. Over 20 RB families and volunteer families came and spent a relaxing and happy holiday together. All of this volunteer work has brought great assistance and warmth to these RB children and their families. It also motivated and created opportunities for more and more members of the Chinese community to participate in service work.

To our even greater happiness, we found that the teens and younger members of CAAMNY were the most passionate group of volunteers. We saw them active in all these activities, be it the Mother's Day picnic or the "buddy family" events. This newsletter of the RB children's foundation you are reading now was also entirely written, edited, printed and published by the young members of CAAMNY. I hope you can feel their passion in charity work through your reading. And I sincerely invite you to continue to support our RB Children's Foundation.

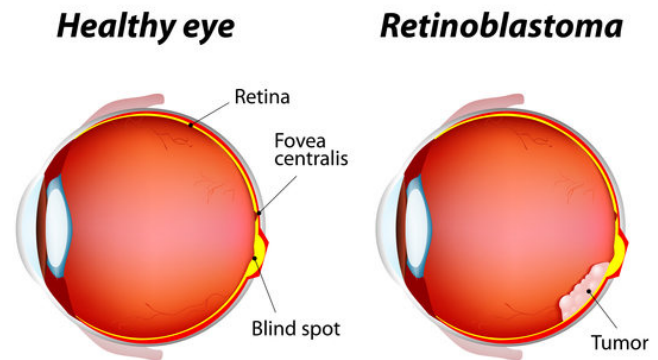
**Thank you,**

**Ying Song**  
**President**

# What is Retinoblastoma (RB)?

By Kenny Tang

Most people have not heard of this rare cancer, but its effects on young children can be devastating. Usually occurring in children between the age of 2-5, this disease begins in the retina, or the back of the eye. In the retina, there are cells called neuroblasts which divide into new special cells. These special cells fill the retina and detect light. However, in some rare cases, the retinoblasts keep growing out of control, causing cancer. Most of these occurrences are traced back to genetic mutations in the retinoblasts. There are two different types of RB, Congenital and Sporadic.



## What treatments are available?

Since RB is such a rare disease, most doctors and medical centers have no treatment for it. Only eye specialists and large cancer centers have the ability to treat it.

Current treatments include:

- Chemotherapy
- Surgical removal
- Stem cell transplant,
- Photocoagulation,
- Cryotherapy,
- Thermotherapy
- Radiation therapy

Although there is not a widely available effective treatment for RB, **9 out of 10** patients are cured, oftentimes with the loss of one or both eyes to prevent the spread of the cancer to the entire body.

## Congenital RB

Congenital RB occurs when the mutation is present at birth. The mutation eventually spreads to the rest of the body's cells, which increases the risk of developing cancers in other parts of the body. 3 out of 4 of these patients have no history of cancer in their family, and their mutation begins during early growth in the womb. Children with this type of RB usually develop the mutation in both eyes, known as **bilateral retinoblastoma**.

## Sporadic RB

Sporadic RB's genetic change is less known about. This type of RB only creates a tumor in one eye, and also has a reduced risk of developing other cancers than Congenital RB. Children usually get this cancer at a later age.

## Further Complications from RB

If the RB tumor is not dealt with, the entire eyeball could be filled by the growth. Deteriorating cells could create more tumors and block the fluid channels in the eye, increasing eye pressure. This could cause Glaucoma, a disease that causes extreme pain and leads to blindness. The tumor can also spread to surrounding areas of the body. This can ultimately end in the impairment of the whole body.

Despite the harmful effects of this disease, there is still hope for RB children in New York. Memorial Sloan Kettering Cancer Center, where the families bring their children all the way from China, is equipped with teams of experts that aim to treat RB in the least invasive and most effective ways.

# Upcoming Events

By Sara Xu

## FALL FESTIVAL

CAAMNY will host a fun Fall Festival at the end of October. All the RB families in New York will be invited to this event. We are calling all volunteers to help us organize games, serve food, and provide entertainment for the families. The time and location are TBD.

## CARE CARS

Children who are going through cancer treatment are fatigued and should minimize their exposure in public areas. The RB Children's Foundation will launch the "Care Cars" program to arrange private car services that will transport families from Flushing to Manhattan for their medical appointments. We will need generous donors to make this program happen, along with volunteers to help coordinate it!

## TOY DRIVE

Christmas is the most joyful time for children all around the world! As a tradition, CAAMNY will organize the "Toy Drive." Brand new toys will be sent to RB families in New York by a "Santa Claus"-- a great memory for each child.

## ANNUAL GALA

The first annual gala of CAAMNY will take place around the Chinese New Year of 2018. This would be the major fundraising event, and it will benefit the RB Children's Foundation. We are recruiting volunteers who have experience in fundraising and organizing special events.



Fall Festival 2016



"Care Cars" - picture by Chris Xu



Chinese New Year Party 2017

# Interview with a Volunteer

By Ellen Zheng



Mrs. Xiaoqing Ma (Right) and RB Children's Mothers

Mrs. Xiaoqing Ma is an important member and volunteer for CAAMNY. She is originally from Shanghai and came to New York more than twenty years ago. Making a difference in the lives of children with RB had been a main priority of CAAMNY's founders when the foundation was established. Mrs. Ma said, "I was one of the initial members that founded [CAAMNY]. I have been helping out the RB kids for more than 2 years. That experience triggered the idea of establishing the RB foundation."

For Mrs. Ma, the idea of giving one's time to the community is very important. She stated, "I have been doing volunteering programs for a long time, not just in this organization, but in other organizations as well. Whether it's helping little kids, the elderly, or families, it feels very rewarding when you are able to help someone in need."

Mrs. Ma is passionate about CAAMNY's role as a nonprofit organization and hopes to promote more volunteerism in the community. She said, "So far we don't have any paid positions. All of our events are organized and run by volunteers. Volunteers are the backbone of CAAMNY, and without them we wouldn't have been able to do any of the activities. We always need more volunteers. The more the merrier."

Moreover, every program has different volunteers for different purposes. Mrs. Ma explained that CAAMNY has two main missions: "One is to promote Chinese culture and to strengthen the bonds between the Chinese community and other communities. The other mission is to help RB

families through our RB foundation." She said that she and other volunteers try to offer as much help as they can. The foundation has a limited amount of money, so it is not always possible to offer monetary help. But for the children who are far away from their homes and family members, the love and care of volunteers can make a great difference.

Mrs. Ma also shared that her favorite volunteering experiences have been the Halloween parties the volunteers have held for the past two years. Participating families gathered together and the RB children dressed up in costumes donated by volunteers. The families shared food, and everyone had a great time. Mrs. Ma said that most of the kids do not know what Halloween was, so the event is an example of CAAMNY's second mission, to promote cultural exchange. Many of the volunteers' children even put together a talent show. After experiencing these events, Mrs. Ma said, "I hope more programs like this can continue with more donations and volunteers."



# RB Family Interview

By Christine and Emily Xu



Lele and his family came to the United States from their home in Guangxi Nanning on September 15, 2016 to seek treatment for his Retinoblastoma. Now two years and nine months old, Lele was diagnosed with RB on August 28, 2016.

Lele and his family's battle against RB has been challenging, both in terms of the expenses and logistics of the treatment and the impact of the cancer on Lele's health and well-being. Lele's father explained that after conducting an initial MRI on September 20, Lele's attending suggested that they choose to undergo systemic chemotherapy. Due to cost purposes, they chose to do chemotherapy in China and returned to do so from September 30

through January 20, 2017. On February 12, Lele's family returned to the States to continue the second phase of treatment, which has been ongoing until now.

Lele's family struggled greatly to overcome the financial burden of treating Lele's RB. His father said, "In order to get immediate cash, we sold our house, which was valued at 165,000 yuan per square meter, for 8,200 yuan per square meter. Even then, we still had to borrow money from relative, friends, and my boss to maintain the cost of the treatment." Lele's health also worried his parents throughout the length of his treatment. His explained, "After chemotherapy, Lele's white blood cell count fell to zero, which could lead to infection at any time. My wife and I were suffering a lot during the whole process."

**In America, Lele's family found that they were not alone in their struggle against RB. They learned about CAAMNY and the RB Children's Foundation through Ying Song and her WeChat group, "Care for Chinese Children." Lele's father is appreciative of all that the foundation has done to help RB families from China. He said, "CAAMNY provides free translations for us and regularly holds parties for the children. Our child really enjoys the activities organized by the foundation, and we are extremely thankful for what they have done for children like ours."**



# Snapshots from the Year









# CAAMNY Celebrates Mother's Day

By Jeremy Shen and Emily Xu



On a sunny Sunday afternoon in Flushing Corona Park, a group of volunteers bustled around on a grassy lawn setting up tables and chairs, laying out containers of food, and preparing gift bags. As volunteers for the Chinese American Association of Metropolitan New York (CAAMNY), they were preparing for the CAAMNY RB Foundation's Mother's Day picnic celebration on May 21, one week after the national celebration of Mother's Day. The event was hosted for over twenty children diagnosed with Retinoblastoma (RB) and their families.

As the volunteers finished setting up the tables for the feast, the children, who were playing together at a nearby playground, began to make their way over to the picnic area. Each child received a small gift bag which contained a pack of bubbles, a foam

football, and a small toy, and they began laughing and experimenting with their new toys. Families of the RB children came together with the families volunteering with CAAMNY, and soon the lawn was filled with conversation and the meeting of friends new and old.

Offering an afternoon of fun, the Mother's Day event was a celebration especially for the mothers of the children seeking treatment in America. The picnic recognized the mothers and all the effort they have put into caring for their children and helping them battle the detrimental effects of RB. Everybody contributed what they could to the picnic, some bringing in a full meal for 50 people and others bringing some treats.





At the center of the table was a marvelous array of food brought in by Mr. Peng, cook from Sichuan, China. He prepared a wonderful lunch of spicy noodles, duck liver, duck heart, chilled cucumber, duck wings, roast beef and beef liver, complemented by his special spicy sauce that he mixed right at the picnic table. A parent of one of a child diagnosed with RB, he quit his job as a business owner and chef in China and came to America so that his child could receive top-tier medical attention. But for today, he decided to take time out of his day to prepare food from his hometown, giving support to other families struggling with RB.

The delicious mixture of spices found its way onto almost everyone's plate; everyone loved the taste of authentic Sichuan dishes, some people were going back for seconds, and the children were asking their parents for more. For some of these families who had full schedules every day, this homemade meal was a welcome break. Also at the picnic were fresh fruits, other home-cooked American and Chinese dishes and snacks. After a delicious lunch, it was time for a celebration.

A couple of volunteers gathered the children together for a game with a parachute. They each held onto a piece of the parachute, waving it up and down and running underneath. The children jumped with excitement, mesmerized by the colors. After that, the kids went to a table to get tattoos and face paint and make arts and crafts, including bracelets and necklaces. For the young children, the small, colorful beads were hard to find and weave onto a thin string; it took a lot of time, perseverance, and determination, but in the end, the results paid off. The children ran off wearing bracelets and necklaces of all colors to play with their bubbles or run around.

While the event was a Mother's Day celebration, it was also one child's birthday. He was the oldest child receiving treatment for RB, and this was a his first birthday party. Everyone passed around slices of ice cream cake and spent the rest of the afternoon enjoying the snacks, games, and company. CAAMNY's first Mother's Day celebration was meaningful for all the children, parents, and volunteers there, and the organization looks forward to its continuation in future years, bringing joy and love to all the members of CAAMNY and the RB Foundation.





# THANK YOU

The RB Children's Foundation has received a generous donation from CAAMNY members and others in the Chinese community. When you donate to the foundation, you allow us to buy new strollers, arrange private transportations for RB families' commutes to hospitals, and organize heart touching events to support the families while their children are fighting cancer. For that, we cannot thank you more!

## **\$1,000 and Over**

WZ Consulting Corp  
Wenjing Wu

## **Under \$1,000**

Elizabeth  
Xianfeng Rong  
Bin Shen  
Yin Jiang  
Yan Yang  
Archegos  
Fuqun CPA, P.C.



# WAYS TO SUPPORT THE RB FOUNDATION

## DONATE

**By Credit Card:** visit our Website

**By Check:** payable to "Chinese American Association" and memo "RB Children Foundation"

**By Chase QuickPay or PayPal:** use our email to make a transfer

Your generosity can help us buy new strollers, arrange private transportation for hospital commutes, and continue to organize our heart-touching events!

## VOLUNTEER

We need volunteers! Volunteers connect with the RB families in New York by visiting them or helping to organize events. Your love and support will touch the hearts of the young children and their parents while they are going through a difficult time in their lives in a community far away from home.

## BECOME A MEMBER

CAAMNY welcomes people who share our passion of serving the community to join the organization. Please visit our website and become a member today!







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Support the RB Foundation today!

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