

The Cystinosis International Conference

~ Dublin - the best memories of my life ~

By Kento Maeda

For three days, from July 2 to July 4, I took part, together with my father, in the Cystinosis International Conference, which was held in a hotel in Dublin, the capital of Ireland.

I was anxious before going to the conference that I wouldn't be able to make friends because Ireland is an English-speaking country and I am naturally shy. But the three days I spent there became one of the highlights of my life, I am very happy I went, and I have lots of happy memories. This is why I have decided to write here what I did and how I remember it.

Before we got to the Cystinosis International Conference venue (hotel)

We flew to Dublin via Frankfurt.

We took off from Tokyo's Haneda airport on a flight bound for Frankfurt on July 1 at 9:40pm. It's a 12-hour flight so it wasn't easy.

Once we got to Frankfurt my father and I had a hard time finding the gate for our next flight as neither of us speaks either German or English, but luckily we found it in the end.

The flight from Frankfurt to Dublin was only 2 hours so it felt like we arrived in no time at all. We landed just after 8 o'clock in the morning.

After we landed, we took a taxi to the venue.

Day 1 (we got to the hotel at 11 o'clock)

Spending time with a fellow patient and his father



When we got to the hotel, we were told that we couldn't go to our rooms until 3pm so we sat in the lobby. I decided to walk around because it was free time, and at the same time two men struck up a conversation with my dad. They were an American cystinosis patient and his father. We had a long chat about cystinosis and became friends (thanks to machine translation), and then we had lunch in a restaurant in the hotel. We carried on chatting about cystinosis and other things over lunch and then took a

photo of the four of us. Time flew by, it was now 2:30 and we checked in to our rooms. I really liked the view from the window in my room.



The view from the hotel 1

Family welcome event

After the patients' gathering ended we all went to a large hall for the Welcome Event. All the patients and their families gathered there for a lively evening. Lots of chatting and laughing. I mainly talked to the Spanish guy I'd sat next to in the bar, and I also spoke about Pokemon-GO with the woman sitting next to me.



Day 2 (July 3)



Barista Gathering

Following on from the welcome event last night, today began with a formal opening ceremony, after which I went to a patients' event aimed at deepening the interactions between patients. Again, I was hesitant about taking part by myself as I don't speak English, but in the end, I decided to take the plunge and participate. It was a coffee tasting session. In the beginning I was at a bit of a loss as I couldn't understand anything the host was saying but the Spanish guy who was sitting next to me showed me how to use

Google real-time translation. The people around me could see that I didn't know what I was supposed to do next, so they helped me out. We were given 16 types of coffee to taste (including one from Japan), but because I never drink coffee, I told the host that they all tasted the same to me, so he said OK! OK! and laughed. At the end we were all given milk coffee to drink. I really enjoyed it despite the language barrier.



Lunch for the patients

We had lunch together after the coffee event.

We all went to a small room on the 2nd floor and had a buffet lunch. The people around me ate quite a lot and they were concerned about me because I didn't eat anything.

I got people to show how to get to the restaurant

There was a dinner planned for the adult patients in a bar near the hotel, and an Irish patient showed me the way to the restaurant so I wouldn't get lost. On the way we chatted about Japan and other things. We split up when we got back to the hotel and then the plan was to meet up with everyone in the bar at 7pm. I forgot what time we were supposed to meet, and while I was wandering around in the lobby I was asked by a group of about 6 patients sitting around a table if I was looking for someone. I told them that I didn't know where in the bar we were supposed to meet the others, and they said that as they were also going that we'd all wait in the lobby. While we were waiting, I chatted with two of them.

Dinner

We all had a drink after meeting up in the bar, after which we (about 30 of us) walked to the nearby restaurant for dinner, which went on until 11pm. While we were there, they asked me if I was in the WhatsApp group, which I wasn't because WhatsApp isn't used in Japan, so I installed the app to stay in touch with everyone. We took lots of photos and chatted about all kinds of things. It was a lot of fun.



Day 3 (July 4)

A morning walk and then updates from the different countries

This was the last day for interacting with people.

Since it was the last day, I wanted to do as much as possible so that would leave me with no regrets.

I got up at 6:30 and when I went to the lobby, I saw my dad and the Japanese doctors. My dad was practicing his presentation, so I went for a 50-minute walk with the Japanese doctors to the nearby lighthouse on the seafront.

The views were beautiful; of a type we don't see in Japan.

When we got back to the hotel I went to hear presentations about patient associations in South Africa, Japan and America.



Themed discussions

Four themed discussions (eye health, muscles, fertility and ketogenic diet) were held after the presentation.

I wanted information about muscle wastage so I went to the muscle session but even with machine translation I couldn't understand what they were talking about.

A walk to the promontory

Looking for someone to talk to I struck up a conversation with a patient from Belgium. We decided to go for a walk and were joined by another patient. We walked along the seafront as far as a huge bronze statue set out on a promontory, where we took photos and then went back to the hotel for the closing barbecue.



The closing barbecue and party



At the barbecue people helped themselves to whatever food they liked and then sat down to eat in a large hall in the hotel. All the patients and families were there. A man with a very loud drum suddenly entered the hall to accompany an Irish music and dance surprise performance. The atmosphere was exciting and festive.



After dinner

We were given free time after dinner.

An ice cream van came to the hotel. We could eat and drink whatever we wanted and take the time to chat. I exchanged phone numbers so that I could stay in touch with my new friends via WhatsApp.

A DJ started to play music at around 10pm, and around 40 people, patients and relatives, stayed to dance. An exciting end to the conference.

This went on until 11:30 and it was great fun.

I gave them hugs and said goodbye to them because I knew I wouldn't see them again the next day as I had to leave the hotel at 7 o'clock in the morning.



Thoughts and impressions

To be honest, I was dreading the very long flight and really didn't want to go.

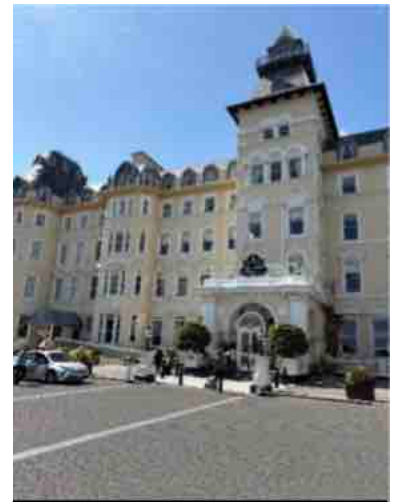
But I am really happy that I did.

Everyone in the hotel was very friendly, and smiled at me when we passed each other. People were very good to me even though I'm shy and introverted.

All the people I met were considerate and kind.

I didn't think I'd be able to make friends with non-Japanese people.

It was all great fun, and if I get the chance I'd love to go again.



The hotel

