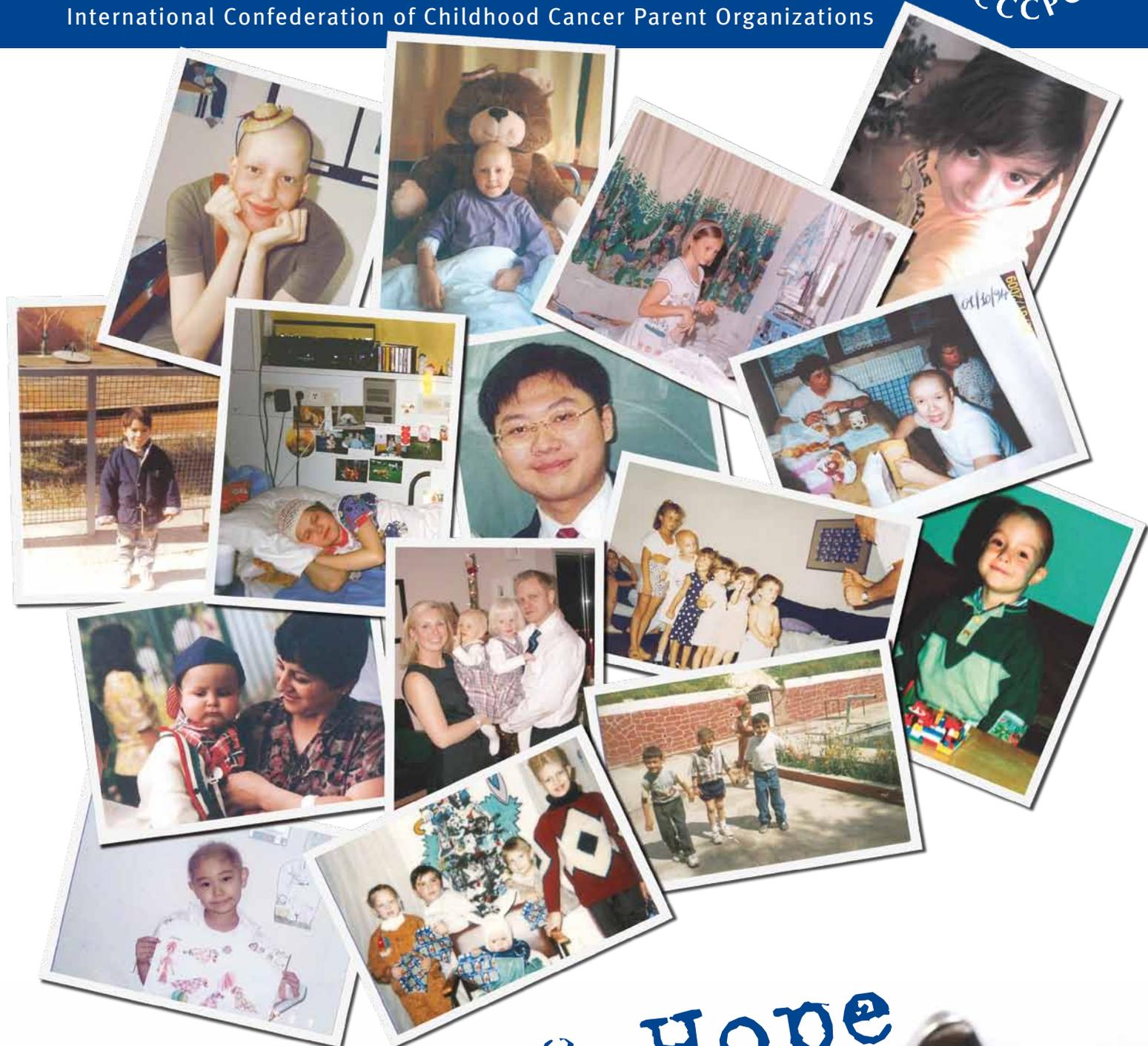


ICCCPO

International Confederation of Childhood Cancer Parent Organizations



Book of Hope





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Book of Hope

International Confederation of Childhood Cancer Parent Organizations

Fifteen stories from fifteen countries
celebrating fifteen years of ICCPO



Fifteen Years to Celebrate

Page



The International Confederation of Childhood Cancer Parent Organizations (ICCCPO) was founded 15 years ago in Spain by representatives of parent organisations from just a few countries. Inspired by the inspiration of ICCCPPO's first president, Jesús María Gonzales-Marín, all the founding members had a common vision: the urge to help children with cancer all over the world in order to give each of them a fair chance for survival.

Meanwhile, ICCCPPO has grown to a strong organisation with presently more than 118 member organisations – and it is still growing. Thus we would like to take this opportunity to celebrate those fifteen years with fifteen stories of childhood cancer survivors from fifteen different countries. All of them have been diagnosed fifteen years ago.

When asking our member organisations for those stories we realized that it was much harder to get them from countries in Latin America, Asia and Africa, which seems to show that fifteen years ago, survival rates were much lower in many of those countries and thus, much less “success stories” seem to be available. We managed, however, to get a fairly even distribution of interesting reports from all the different continents and think these reflect the situation in so many other areas.

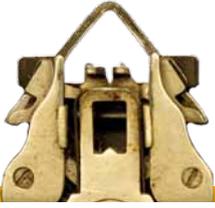
Today, we are glad to know that much has changed for the better - even in low income countries, even in areas where only a few years back the treatment of children with cancer was virtually not possible. Parent groups gather regularly in international and regional meetings and by sharing ideas, experiences and information, all have learned a lot - learned to influence politicians in their areas, learned to work with health system officials, learned to be actively involved in changing the situation at their specific hospital.

And ICCCPPO has been able to help more and more, enabling many more participants to join the meetings by granting stipends not only to parents but also to survivors who started their own meetings several years ago. As the confederation has become stronger, the founding of a fund raising arm of the organization made sense, called World Child Cancer. This non profit foundation was established primarily under the driving force of our deceased president Geoff Thaxter (Chair from 2007 to 2008), whose vision “no child should suffer” brand marks the foundation’s goals. With the help of World Child Cancer the international confederation ICCCPPO is able grant money to projects that are designed to help in areas where support is still lacking.

As ICCCPPO approaches the future the community of parent organisations can be proud of the success. However, much has still to be done in order to reach our common goal that “every child with cancer should be treated according to the best known standards to have a fair chance to survive this dreadful disease.”

The stories in this booklet are wonderful examples of courage, faith and gratitude. They are telling us in ever so different words and ways about the patients’ experiences, the struggle to overcome their disease and master the time after. These young people are grateful for being given a “second chance” and thank all those who helped them along the way: the doctors, the nurses, their families and friends. They are representing what ICCCPPO is striving for.

The ICCCPPO-Board
(May 2009)



Petra

Petra lives in Austria. She was diagnosed with acute lymphoblastic leukemia on June 8th, 1994. At that time she was nine. Petra is now 24 years old and has a two year old son.

It all began with unexplainable bruises and a stabbing pain in my hips. After many visits to the doctor, many examinations and X-rays, eventually leukaemia was diagnosed. The paediatrician gave us the choice of whether we wanted treatment in Linz or Vienna. We were stunned and speechless at first, it felt as if the rug had been pulled away from under our feet. At this point we realised for the first time how serious the illness was. Eventually, we decided on the children's hospital in Linz because the distance was much shorter (80 kilometres).

We drove home, packed the most important things and drove to Linz. My little sister (5) was taken to my aunt for a short time.

The next shock came when we were standing in front of the ward: We saw the sick children with no hair, "chained" to the infusion stands. I still could not believe that I would have to spend the next part of my life on this ward, that I would belong here. The team on the oncology ward was very nice and empathetic with me and my parents. The ward nurse Beate prepared a room for us immediately. After several meetings of the doctors with my parents, blood samples taken and much more, followed what was for me and my mother the most horrible night we had ever experienced. On one hand I was happy that the pain had eased, but on the other hand I was terribly afraid of what was laying ahead of me. I shared the room with a seriously ill brain tumour patient, a situation that made it very hard for me to believe that I would ever be able to recover. It was a very long night and I could not believe that this was my fate.

Then it all happened at once: In the morning, I had a bone marrow aspiration and around noon, the doctors were already giving us the result: acute lymphoblastic leukaemia. Then the senior physician explained the therapy plan as well as the procedure and the side-effects. Now everything took its course: All those tests and then the cortisone therapy to suppress the cancer cells which lasted a whole month. After these four weeks came the second bone marrow aspiration. Here it became apparent, however, that despite of the therapy the cancer cells disappeared much too slowly. So, I was classified stage three (high risk), which meant relapse high therapy. It consisted of nine blocks of chemotherapy every six days and a two-week break. It was a high-risk therapy with additional central nervous system involvement which meant additional lumbar punctures. But after many painful months, finally the last day of treatment came.

During the treatment I met many patients and mothers. A lot of friendships were formed. Whenever a child died, it was a very saddening blow. But then there were also many children who got well again, which encouraged us. From the children's cancer charity group (Kinderkrebshilfe) we also received a lot of help and support of all kinds.

My mother stayed with me all the time. Only at the weekends she drove home to my little sister, and then my father stayed with me in the hospital. During the week my sister was at my aunt's, who became a "surrogate mother" for her in this time.

I could not go to school during chemotherapy. Fortunately, thanks to my former teacher, I was able to finish the fourth grade of primary school successfully, because she taught me at home for free. So I was able to pass the tests and homework. I was also given support from the hospital teacher. When I was finally (after nine months) allowed to go back to school I was delighted that I would be with my friends again. But I had mixed feelings about how my schoolmates would react. All my doubts vanished when I entered the classroom. I was given a warm welcome and everyone had a present for me. I was over-joyed, they showed a lot of interest and asked me many questions. Maintenance therapy followed, with blood tests in the hospital every two weeks.

In the following three years my family and I travelled to Styria for a holiday organized by the Upper Austrian Children's Cancer Charity group. These were unforgettable weeks for everyone. We got to know many families with similar fates and friendships grew from this.



In October 1996 my brother was born.

Until January 1998 it seemed that everything would be all right again. But a common cold changed the situation dramatically. My cough, the fever and a feeling of weakness were not improving at all, rather getting worse daily. My parents and I always tried to suppress it, but we could not escape the feeling that this might be a relapse.

At first we drove to the nearest hospital, where they made a blood test. At that point in time I had only very few platelets. I asked the senior physician whether it was the same illness again. He said that it probably would be something else and I would therefore have to be given inpatient treatment. We then did not stay there but drove to the paediatric hospital in Linz immediately. Unfortunately the puncture confirmed our suspicion: It was a relapse. This was one of the worst moments in my life. We stood on the ward completely shocked and helpless. The worst thing was that I knew from the start what would be laying ahead of me. My mother did not know what she should do with my little brother (1 1/2 years old) and how everything was going to continue.

After we had “digested” everything to some extent, the attending doctor informed us about the procedure for the following days. I was given the same therapy as the first time and my chances to be cured dropped to about 25 percent. A bone marrow transplant was therefore considered. Unfortunately, our big hope that my brother might be a compatible donor was not fulfilled. It was quite a disappointment for all of us. Nor did they find a match within the rest of my family. So, they started the search for an unrelated donor. During the entire search, I got chemotherapy. But this time it did not go as well as in 1994. The cortisone therapy made my blood sugar level rise rapidly. I was allowed to go home one day, but a short time later, I was called by the doctor because I had an extremely high sugar level. On the way back into the hospital I had a black-out and collapsed. By administering insulin and different intravenous medication they got everything under control again.

In addition to the fact that I had to watch what to eat and to inject insulin, further setbacks led to additional hospital stays. First of all I had a serious inflammation of the digestive tract - starting from the mouth through to the bowels. This meant that I could no longer eat anything at all and could not go to the toilet. It was really terrible because everything, including my anus, was full of blisters and my bowels still had to be emptied. When I finally managed this, I suddenly had a seizure. I was taken to another hospital by the emergency doctor in order to get a CT done, which showed that I have had an epileptic seizure. With the last blocks of chemo the situation got a bit better.

Now came the day when we were told that I would be given a transplant. First of all my parents and I had to go to Vienna to the St. Anna Children’s Hospital to meet with the doctors and to discuss the precise details of the procedure with them. They explained to us the method of treatment, the chances of being cured, the side-effects and long-term consequences. Among other things, I was told that I would not be able to have children because of this treatment.

The date was set for the 22nd of May 1998. We drove to Vienna for the transplant. With a heavy heart I said goodbye to all my friends and family because no one knew how it would all turn out and when I would see them again. The family helper, whom we definitely needed during the second illness, was with my little brother. Unfortunately the helper changed constantly, so my little brother often woke up to a “new” face and had to stay with a “strange” person.

We did not know, however, who could be a possible donor, either my father or my mother or an unrelated donor. Until then there was no donor who was a one hundred percent match. The taxi was waiting and the journey into the unknown began. Arriving in Vienna, I went to the bone marrow transplant unite. The doctor greeted us and said: “We are not transplanting yet! A matching donor was found yesterday and everything will have to be tested first!” When I heard this I did not know if I should be happy or whether I should ask the doctor why he did not call us beforehand. I had packed for three months anyway. At

home everything was arranged with me and my mom staying in Vienna, while my father, brother and sister were at home. Suddenly everything had changed. It was agreed that I would be given another block of chemo and then have a five-week break until I should receive the transplant.

During this chemotherapy, certain drugs could no longer be administered, because my heart was too weak for this and they would cause organ damage. Eventually it was a reduced block of chemo for one week. So I went back home and I was able to recover from the stress and the strains. While I was waiting for my next bone marrow transplant appointment, blood counts were made by way of the Hickman catheter which was already inserted. Of course I was worried with every check, hoping that everything would be okay, because it was five weeks in which I did not receive any chemotherapy.

At the beginning of July in 1998 it was serious. We drove to Vienna. In the preparation week I was still allowed to go outside, and we walked around Vienna as much as possible. At the weekend my brother, my sister and my father visited me and stayed overnight in the McDonald House nearby.

Now started the conditioning, that is: all cells were destroyed with radiation and chemotherapy. The first four days we went to Vienna General Hospital twice a day for irradiation. Seeing all those elderly patients we wondered why I as a child had to undergo such a treatment. And they were even given much smaller doses than I received. It was very frightening to know that my entire immune system was destroyed and that I would not be able to live without the bone marrow of the donor. On the fifth day, I received another chemotherapy over four hours to kill the last remaining cells. This was done in the so called “clean room”. A day before the transplant I had another tube inserted and the 14th of July 1998 was the day of my transplant. The nurse who had picked up the bone marrow from Bologna (Italy) was back at St. Anna Children’s Hospital in the evening. The bone marrow was given intravenously from a “life-saving bag,” which looked like a blood bag. Now began the difficult time to wait and see if the new bone marrow was accepted. After ten days the first leukocytes could be seen. Until this point I was tube fed and my pain was relieved with morphine. Finally the day of discharge came. But it did not take long until I had to go back to hospital with shingles.



The next setback happened at home. I blacked out and fell from the toilet. I could no longer move and I was taken to the hospital by emergency ambulance. It turned out that I had vertebral body compression. The cause was osteoporosis.

sis, which itself was caused by the high level of cortisone. But unfortunately, one could not reduce the cortisone because it was needed to suppress the cells. Basically, it was a terrible time for me, and then I had another epileptic fit. It was the most dreadful time, which healthy people cannot imagine. Repeated attempts to discontinue the cortisone did not work.

When we managed to get everything under control, the worst thing was still to happen. It started with harmless diarrhoea. In the Linz Hospital acute bowel rejection was discovered. As they could not control my pain I was transferred to Vienna. The pain was terrible and I was exhausted. I was given morphine and more cortisone to be able to deal with the rejection. We were close to despair. My mother spoke with the doctor and he also said that the situation was very serious because, if too little cortisone was given, the GvHD (rejection) would not be under control and if too much was given, my body would no longer tolerate it. He also seemed to be very concerned about my condition.

Completely weak, I left the hospital after three weeks. Outpatient appointments followed almost daily. In this period home schooling began. Different teachers visited me at home. It was a good experience to feel like being part of things once again. With the treatment of the relapse I had missed one school year. So I did not have so much to catch up on and going back to school was not so hard. But I went into a new class, which was not easy for me at first. I would also like to mention that I was given confirmation classes at home, too. The priest from our parish said he would ask the bishop if I could have confirmation at home in case I still had a low blood count. It was a very nice gesture. But in the end, my confirmation was in the church together with all the others.

During the difficult period I was also given a lot of help and support, especially from the Children's Cancer Charity group (Kinderkrebshilfe). We were able to go back on holiday to Styria, too. It all started to get better. I had to take fewer and fewer tablets until there were only those for the epilepsy left. I finished the lower secondary school and then went to a business college, where I graduated with a general qualification for university admission. That was also the time when I met my current boyfriend. So the question of whether I could ever have children became an issue again. I asked my attending doctors many times if I could really not have any children. But I was told each time that the whole-body irradiation had left me infertile. This was a big shock for me and my boyfriend, because we both really love children. So I concentrated on the start of my career - but in vain. To my surprise, I was pregnant! It was unexpected, but we were very happy. On the 20th of January 2007 our son Dominik was born, a healthy little baby.

I am now 24 years old and my family and I are very well. I hope that I can start my professional career in the next few months and that in the coming years another baby will come along.







José Ignacio

José Ignacio lives in Chile. He is the youngest of three brothers. In September of 1994, when he was seven months old, he was diagnosed with high risk acute lymphoblastic leukemia, and at the age of four he relapsed. José Ignacio is now 15 years old and currently in tenth grade at Weber School. His dream is to become a professional soccer player.

I am José Ignacio. I was born September 2, 1993 in Rancagua, Chile. When I was seven months old, I was diagnosed with high risk ALL and hospitalized in the Dr. Exequiel González Cortés Hospital, located in Santiago, in order to begin my chemotherapy treatment immediately. During this time, my mother traveled everyday by bus from Rancagua to Santiago to see me and find out how I was doing. She would leave my two older brothers in the care of my father, with neighbors or at relative's homes so she could be with me. It was a stage of sacrifice and putting things off for all of us. When this period was over, we continued traveling together to continue treatment.

After four years I had a relapse and had to start everything over again. But this time, the treatment was much stronger and more aggressive than before. I was very ill, because the chemotherapy caused inflammation of the intestinal tract, from the mouth to the anus, and I was in hospital for a month and a half. During this time, again my mother was always with me, never leaving my side. But it hurt me that it was my fault that she couldn't be with my brothers. As a result of my low blood count, I often had pneumonia, which caused me to be in hospital for long periods each time, far from my brothers and my father. I couldn't play with other children and I had to be very careful not to have contact with other sick people. In 2000, the doctor told my mother about a vaccine to lessen the frequency of my pulmonary infections. They gave it to me, and I began to recover and had fewer incidences of pneumonia.

I remember a couple of funny things that happened in the hospital during some of my long stays. One of them was: Because I was very restless when I was small, I moved around a lot in bed, until one day I fell out and was hanging by one arm. I was very scared because it mobilized all the medical personnel of the cancer unit. They examined me and took x-rays to see if I had broken anything. Thank God, they didn't find anything and I came out without a scratch from the fall. The other time was during a stay in the hospital that the doctors, nurses and aunts (volunteers) affectionately called me "troublemaker" because, since I was more restless in comparison to other children, I was always going from one place to another, happy and content, in spite of my illness. Only when I had a fever I calmed down a little bit. I was a child with a lot of energy. One time the doctor was very worried after a chemotherapy treatment because he thought that I was weak and didn't know what could be the cause, because my reaction was different from usual as he found me very quiet and not moving very much. But after a few hours, my mother and the doctor were relieved when they saw me jumping on the bed and returning to my usual pranks. Until today, some of the doctors still call me affectionately the "troublemaker".



When I finished chemotherapy treatment in 2003 and I was healthy, I felt very happy and content because I was able to go back to be with my family, my parents and brothers, and I was able to do everything I couldn't do before in my childhood because of the amount of time spent in the hospital. Today, I only have to go once a year for controls until I'm 19, and I depend on vaccination to keep me from getting pulmonary infections.



When I found out that I had cancer, and became aware of how advanced and aggressive my illness was, I felt very frustrated, but it also gave me strength to keep on fighting. I have many dreams yet to fulfill: a wonderful life with my parents and brothers, who gave everything for me to come out of this and to get ahead in this world.

My biggest dreams are to have a beautiful family and to be a great and famous soccer player. Now I have friends and I enjoy life more than anyone else.



... called me “troublemaker”



Henry

It came as a terrible shock to my family when I, Henry, as 14 years old teenager was diagnosed with acute lymphoblastic leukaemia (ALL).

I was having a long vacation in America in the summer of 1994. I felt tired and got frequent bleedings, but I attributed the fatigue to the excitement about my trip. When I was on the return flight back to Hong Kong, I felt even worse during the long hours of the flight. Afterwards, I began to experience with my health, a routine medical examination discovered nothing more serious, but only blood clots coming out from every bleeding of my nose. I was diagnosed the have a normal flu infection at that time.

I had been unwell for about a week. But after taking medicine for one week, I noticed some abnormal red spots (petechia) appearing on my hands and legs. I went to consult my doctor again and he asked me to have a full blood test done immediately. Fears started coming to me because of his serious tone.

Wednesday, the 31st of August 1994, 7pm - is a date that will stick in my mind forever. My parents and I were called back to the doctor's office to talk about the blood report. When we got to his office he told us that I had leukaemia. I was in total shock and wasn't even a hundred percent sure what leukaemia was. My mother and I broke down in tears when my dad was still calm and listened to the detailed explanations by the doctor. He recommended us to go to Hong Kong Baptist Hospital for further examinations in order to confirm the diagnosis. It was a busy night for us. I was transferred to the hospital. Finally, the consultant haematologist met us in the morning and said there were abnormalities in my blood and he gave us the recommendation of going straight down to the Queen Mary Hospital which had a team of professionals for this disease.

Thus, I was immediately transferred to the Queen Mary Hospital in Hong Kong where I spent the following months. Within an hour I was examined by a doctor and asked loads of questions and they took even more blood. By then, Dr. S.Y. Ha made a meeting with us to explain ALL in detail and the treatment plan. We were taken into a meeting room and asked to sit down. That sinking feeling filled me again. The doctor and the nurse were both kind and considerate. They calmed me down and told me what the matter was, nevertheless lots of my tear followed.

I was told to stop all my normal activities and my school life because I had to pay full attention to fight against this disease in the following months. I would get a two year treatment with chemotherapy daily. Once a month, I would go for a five day course of a stronger dose. I also had frequent blood tests. The blood samples would be taken directly, because they did not insert a Hickman Line during my whole treatment. This really made me fear every puncture for blood-taking. As time went by, I started get used to it. Certainly, I also had to take numerous different drugs over the two years.

Since diagnosis I have been in and out of the hospital for treatment. During the first year of treatment, I felt unwell but lucky, as the side effect were not so serious. Despite this grueling treatment at such a young age, I kept a positive attitude and rarely complained about the treatments I had to go through. I believe that the substantial support from God, my parents and my friends provided me with strength to fight against this disease. Also the hospital chaplain encouraged me during this hard time.



Certainly, my parents' lives had to change dramatically. I stopped my studies during the intensive treatment in the first few months. I was not allowed to go to any crowded place. So, I was beginning to feel bored. During the treatment period, my parents were busy to take care of me every day. Especially my mother brought food to me and stayed with me. I feel so grateful for the love of my parents. After the first six months, the treatment showed to be effective. So, a bone-marrow-transplantation was not necessary in my case. After the two years of hospital treatment, I still had to take oral treatment and get regular check-ups monthly. With the good progress on recovery, my doctor allowed me return to school.



When I returned to school, I needed some time to adapt again. As I had spent a year with intensive treatment, my studies lagged behind. Thus, I had to get used to a new environment and new classmates. I believe that I am the one who was really lucky with the care and concern I received from the principal of my school. He communicated with my parents about the special arrangement for my return and allowed me to take the PE class with flexibility. He reminded me to put my health to be first priority.

I needed to take a leave frequently for regular check-ups and thus I often missed classes that may have affected my academic performance. As my teachers understood my situation, they were willing to give me additional tutorial help when ever necessary. I did not hesitate to share my illness history to others and never was ashamed about it. This may be the reason that I got support from my teachers and classmates. I understand that care and support are essential to make patients recover better. Thus, in 1998 I joined the Student Health Care Experience Scheme from the Hospital Authority, in order to share my experience as a positive example with other patients.

15 years after my diagnosis, I still have a yearly check-up in the hospital. I really appreciate my doctors and nurses for their sincere caring during these 15 years, so I could return back to a normal life. This disease let me learn a lesson to be strong and more mature. After my undergraduate studies, I now work in the field of quality management in an international enterprise. I hope that my experience can be shared with every child who suffers from this disease and may give them support in winning this fight.





Salla

Salla lives in Finland. She was diagnosed in 1994 with acute lymphoblastic leukemia. She was then eight. Now she is 23 and works as a registered nurse. In 1994, Salla lived in the city of Rovaniemi, which is situated in the northern part of Finland commonly called Lapland.

At the time of the diagnosis she was a second grader whose class was then to go skiing to a nearby mountain. Her mother got worried about Salla going to school that day, because she had not been feeling well the day before. But Salla looked forward to the skiing trip and she insisted on going to school.

Salla remembers that she was able to ski to the mountain which was 6 kilometres away from school. After reaching the mountain, she felt sudden dizziness. Salla told her teacher she did not feel well. She remembers that it was a real ordeal to ski to school from the mountain. All she could do was cry because she was so exhausted.

In the evening, Mother and Salla went to see a doctor, a GP. After Salla's blood tests were ready, she was sent to the district hospital of Lapland for further examinations. The next morning Salla was sent to a bigger hospital, the University Hospital of Oulu, which was 200 kilometres away from her home town.

After the tests and bone marrow biopsy at Oulu University Hospital, Sanna was diagnosed with ALL. It was hard for a school girl of her age to lie in isolation at the ward for a month. During the isolation, she was greatly comforted by the daily mail, postcards and letters her school mates and girl Scouts sent her. Especially her godmothers and godfathers took pains to make her happy, and sent her presents to the ward.

At the ward, the hospital school teachers gave Salla lessons, and her Elementary School teacher came to her home to teach her. When Salla was able to go back to her old school, she had no hair. That is why the school mates kept teasing her. They did not understand why Salla looked different now.

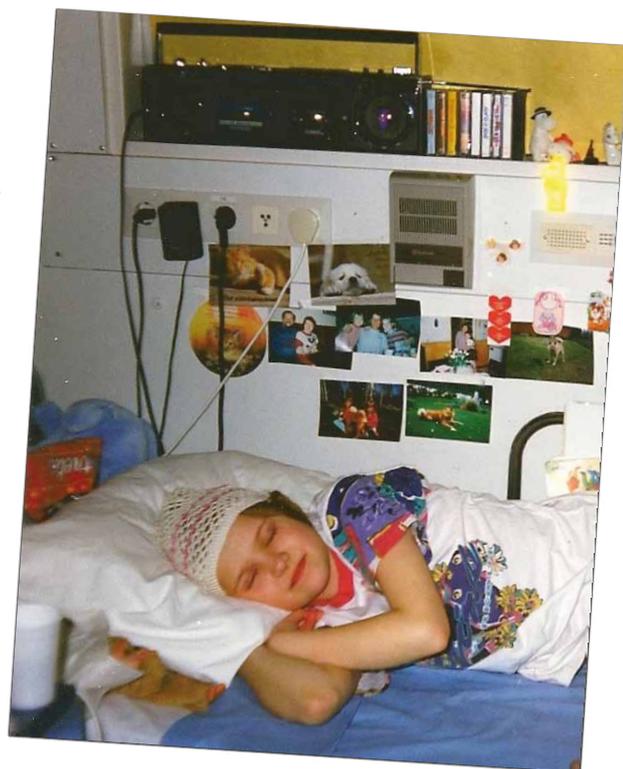


Salla wanted to stop the teasing and prepared some informative material at home to give the entire school an oral presentation on what cancer really means. So she did. She told them cancer is not contagious, and her loss of hair is due to cancer medication. After that, the teasing stopped.

During and after the treatments, Salla participated in the rehabilitation courses arranged by SYLVA, the Finnish association of parents of cancer children. Salla was really happy to meet others of her age who know what she had been going through. She considers it a great asset that she has been able to talk to other survivors. As late effects of the treatments, Salla now suffers from asthma and migraine. Moreover, her teeth are smaller than normal. Sometimes she gets depressed, but otherwise she is a happy and active person. Her hobbies are dancing and music.

Salla finished her studies one year ago and works now as a registered nurse at Peijas Hospital in Vantaa, for she got a job in southern Finland. She has also been trained by SYLVA to act as a support person for cancer children and teenagers. Salla says that it is important to help others.

And there are romantic news: for next autumn she will be married. Salla and her future husband are planning to go back to Lapland some day and build a house to be their home.



200km away from home ...



Sarah

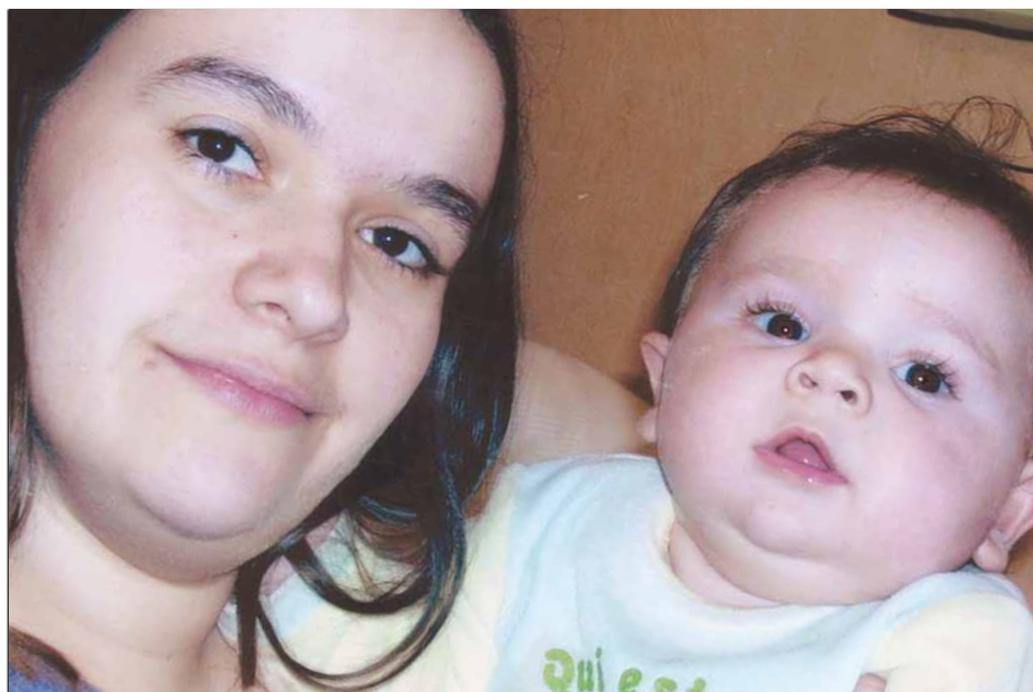
Sarah lives in Cavailon (famous town in Southern France where they grow juicy melons). In May 1994 she was diagnosed with Burkitt's Lymphoma, she was then 11 years old.

She was treated at the Children hospital of Montpellier in France, at the end of the chemotherapy a dried ovary had to be taken out. She went back to school in Oct 1994 and did not want to wear any wig, nor scarf. She remained bold without any problem among her school friends.

She participated in two week-ends at Disneyland Paris, for which she had to take the plane for the first time. This was organized and donated by the local organization "LA CLE".

Her parents were staying at the "LA CLE" parents' house right opposite the hospital during the whole treatment and got help and moral support. The volunteers regularly visited them at the hospital.

Sarah is now 25 years old, working at a Kindergarden and just has a baby boy "Lorenzo".





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"LA CLE" parents' house
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Constanze

Constanze lives in Germany. She did her vocational training in dressmaking when she was diagnosed with Morbus Hodgkin in February 1994. The treatment finished in October 1994 and she returned to the apprenticeship in February 1995, graduated in August 1996 and specialised in clothing technology. She is now working in this field for nine years and is married since September 2006.

In September 1993, shortly after my graduation from high school, I started an apprenticeship in dressmaking. After a few weeks I realised how exhausting the new routines in the working world were to me. Very often I was tired, outworn and suffered from fever attacks accompanied by nocturnal sweating (annoyingly enough, this happened mainly on the weekends). Additionally I caught a lot of infections and lost weight without actually wanting to.

I have to admit that I had always been scared of needles but my Granny wouldn't stop nagging and pushed me to go to the doctor. Finally, making an appointment seemed to be the lesser of two evils. Although already at the tender age of 21 years, I was still seeing my paediatrician which turned out to be a blessing retrospectively. She never gave up and made sure that I eventually landed in the practice of an oncologist. After what felt like 120 examinations my doctor was able to give a kind of "tentative diagnosis". I still remember our conversation very well. I heard terms like Morbus Hodgkin, loss of hair, spleen removal and that while they were doing that, they also wanted to take some tissue samples. My question about how urgent the surgery really was received a short and convincing answer: the oncologist said that in the case that his assumptions were correct I should go ahead and enjoy the summer. It would be my last one if I refused treatment. I did not need any more convincing.

Weirdly enough I never thought that I could have cancer, although the mentioning of the „loss of hair“ should have given me a hint: it is a typical side effect of cancer treatments, after all. My doctor advised me not to go ahead and research the facts behind the term „Morbus Hodgkin“ – at least not while we had no confirmation of the diagnosis yet. I followed his advice, but only after I had read that the survival rate was at 70%.

On the 17th of February I was admitted to the hospital as an in-patient. The next day I had a bone marrow puncture in the hip. This was a very disagreeing experience. Although one can numb the surrounding tissue it does not help with the actual suction of the marrow which is very painful. The orderly who assisted the ward physician suffered from a squished hand after this procedure. He had been so nice to offer it to me to hold on to before. Because the first needle had bent out of shape I was treated to a second try. After that I weakly joked that now I would like to have an ice cream treat as a reward, thank you very much. Guess how surprised I was when a few moments later the orderly returned – with a sundae in his hands!

I was operated on four days after I had been admitted to the hospital. Coming out from anaesthesia I was convinced I was in heaven for a short while. But with increasing visual acuity the alleged angel in front of me turned out to be a very mundane visitor in white scrubs. In a second sensational turn of events my friend had managed – using her considerable charms, I bet – to smuggle a giant

stuffed panther through all hygienic sluices. The panther resides on my parents' couch until today. Barring those events I felt that the time in intensive care was very exhausting. I hardly got any sleep at all, the monitors beeped through the night and someone was always bustling about.

Back on the ward, things quieted down a bit. My first foray to the bathroom was abruptly stopped by the wound drainage – the bag was still tied to the bed, something I had successfully repressed, it seemed. Well, good job, boys – the suture did not break!

To regain my strength I had to walk back and forth on the ward corridor from now on. Apparently, my body posture was not back to normal yet. My sister turned out to be a relentless personal trainer for me, which I needed, although I was of a different opinion back then. About a week after the surgery the clinical findings arrived. My parents and I waited in my room for the doctor. I believe that this was the first day that I completely realised that we were talking about the word CANCER here. At any rate, I started crying my eyes out when the preliminary diagnosis had been confirmed. Crying was still my main occupation during the next day. My biggest fear was the chemo. I could say it was the fear of the unknown. In my only existing diary entries from that time I wrote down my fears:

Endless vomiting, long hospital stays, fears that neither my mental nor my physical strength would be strong enough, that the treatment would not be effective and that I would be swallowed by all these negative thoughts. A giant help during that time was listening to music. The soundtrack of “Sister Act” often managed to lift my mood and to make me come back to a necessary confidence. I still have the original tape from back then.

The first round of chemo started on the 8th of March. The scar from the spleen removal had healed nicely, just in time to bear up against the intense puking attacks. During my first chemo I was given Cortisone. This triggered a tiny binge which I came to regret horribly only a short while later. My body apparently decided to chuck out everything that was not willing to pay its rent and I found myself occupied with puking for quite a while longer than what was strictly necessary. But I learned from my mistakes and from now on I carefully avoided eating a large meal before chemos. At one point my hair started to get thinner, too.

On the day I decided to completely shave my head something very funny had happened. I had a bath and washed my hair. After getting out of the tub I realised that the bathing water was covered with a thin film of hair. But only when I started blow-drying my hair it finally happened: Out of the corner of my eyes I could see how I was actually blow-drying the hairs off of my head. They



were gone with the wind, so to say. I had had such a giggle over the whole situation. Back then, my sister and my cousin were not as amused. Partly, because they did not know how to deal with the situation, I think. Even today I have to smirk a little when I think of this story – it's a lot like retroactive slapstick. After the blow-drying incident I looked positively plucked. A look I didn't care to wear in public. Consequently, my sister had to first cut the remaining hair and then shave it - a weird feeling and especially very cold on my head during this time of the year. I decided on wearing scarves instead of a wig. With make-up one hardly noticed that I was bald. Many people asked me why I was wearing scarves and couldn't believe that I had no hair whatsoever underneath.



Finally, after the first round of chemo, I was allowed to go home for about four weeks. By now, I could fit into a size 6 – 8, easily. Since I am 179cm tall, I looked rather skinny. But back home I was coddled and spoiled, so that I was able to face each round of chemo with new-found strength. One time my blood test came back with very bad results so that I had to have a blood transfusion. Next to the acute fear of cancer I now was also scared of catching the HI-virus. During a long walk with my mother my frustration got the better of me and I suggested “Died of AIDS instead of cancer” as my epitaph. I think I shocked my mother completely. A few weeks after my treatment I was able to do a test which relieved me of this anxiety.

I got four rounds of chemo altogether until the end of May. I bore them more or less well. In between rounds I could always go home. I turned one little thing into a tiny ritual: every time I felt better, I walked to a kiosk. I always bought a small pack of chips and a coke. I kept doing this for a long time even after the treatment – always after checkups. To put some variation into the daily routine of hospital life I went on some small excursions from time to time. Most of those were not really part of the therapy plan but they helped at least quite as much. I remember treating myself and my cousin to a glass of wine in a Chinese restaurant around the corner one evening. Some of those excursions were nipped in the bud by an overzealous nurse, though.

After the chemo therapy followed radiation therapy. Every day for six weeks I was treated with high dose radiation – 30Gy – on all lymph nodes. The first three weeks they treated the nodes above the diaphragm, then underneath. Since my spleen had already been removed they manufactured a block of lead for this part of my body. To pinpoint the exact place where radiation was to be directed at the doctors painted a kind of cross line on my thorax. I was not allowed to wash this off. Despite this direction I had to go back to the radiation clinic for them to paint the cross line back on. I was mortified and I nearly tried to retrace the faint outlines of the old cross line to avoid admitting that I had washed most of it off. But finally I was more scared of getting it wrong and thus getting radiation in the wrong places than of going back to the clinic.

I did not feel anything about the radiation itself. My throat hurt extremely. After the first three weeks I was not able to swallow even yoghurt. Despite preventative medicine it hurt too much to swallow, so that I rather ate nothing

at all. Apart from the medicine not working I could not stand its taste anymore. Luckily those were the worst acute side-effects from radiation during the six weeks.

One of the great by-products of radiation was the brand-new awning that my parents had installed over our terrace. My skin had to be protected from direct sunlight during that time. I was very happy about the awning, because now I could spend time outdoors during the day.

At the end of September the fifth and final round of chemo was due. A once intended sixth round had been cancelled because the prophylaxis did not correlate with the bone marrow toxicity anymore.

To survive the situation mentally intact I employed strategies such as repression and distraction during the treatment. I would hardly have managed the time without my family and friends. Someone was always by my side, even when I voiced my fears in angry outbreaks. I never felt alone. My doctor, his colleagues and the whole ward supported me, each and everyone in his/her own way.

I was discharged on the 12th of October. After rehabilitation in the Black Forest in January 1995 I re-entered my vocational training and graduated in August 1996 with good marks. After one year worked there I decided on further education to become a clothing technician. I have been working in this field for nine years now. In 2005, I met Marcus and in 2009, we will celebrate our third wedding anniversary.

Since then a lot of time has passed and I am not scared of a relapse anymore. The yearly check-ups turned into a ritual which I even celebrate a little bit, just for me. My cancer will always be a part of me, a part which in time I have learned to accept. One could even say that we grew to be friends. For me, this is the best way how to live with the illness.

There were times after the treatment when I managed to put the cancer far behind me, hardly thinking about it. But ignoring it was not the solution. It finally caught up with me and I realised that it is unnecessary to leave this part of me out. The exchange with other cancer patients whom I met on different seminars organised by the German Parent Initiative helped me a lot. There was a lot of common ground to discover. I call it the cancer-world. This world is something very special and I was given the opportunity to discover it as well as the normal world. I try to make the best of both worlds. Sometimes I consciously recall the cancer time; especially when the everyday grind and all those imagined problems start to use up too much space and energy.

By now I found new priorities in my life. I am dreaming of buying a house and having two healthy children. The great thing is that my husband shares these dreams with my.  And that's not the only reason I love him so much.



Gudbjörg Vigdís

Gudbjörg Vigdís lives in Iceland. My life changed forever in 1994 when I was diagnosed with cancer. What I went through in the months that followed has affected my life in many ways since.

I noticed the first symptoms in November 1994. I had always been healthy and in good shape, but as winter progressed I felt weaker and weaker. I found it hard to exercise and always craved to go directly home to sleep after school. Furthermore I experienced constant headaches, repeated nosebleeds and impaired vision. When I was at my worst I wanted above anything else to lie down in a dark room because I was so sensitive to light, and my headaches increased day by day.

My mother had taken me to see a doctor earlier in the autumn but the GP found nothing wrong. When the symptoms got worse she took me to an ear, nose and throat specialist who found abnormalities that needed further examination. After a few x-rays and samples we had the result: cancer in the nasal cavity.

The diagnosis was obviously a great shock but it wasn't until a few years later that I realised the gravity of having cancer. It could be considered a blessing that I was just a happy-go-lucky teenager and oblivious to the dangers and threats of the world; my main concern was how lame it was to have cancer in the nose! I remember only once talking about death during my treatment; it was when I asked my mother to "please make sure I have my walkman in my ears if I die. I'm afraid I'll get bored." My attitude has since altered and matured, having seen many friends lose their fight with the disease and having experienced its horrible consequences in my career as a nurse; I now appreciate the true extent of my good fortune.

The months following my diagnosis were difficult, but in hindsight this was a good time. I got to know so many great people; the hospital staff, who do amazing work, and all the other children who were being treated and their families. My mother and I are still in touch with some of them, because we share an experience that other people cannot really understand. My mother carried this burden all by herself, and I cannot imagine how she felt having to watch her only child struggle with this malignant disease. Nevertheless, we had good friends and family from whom we could draw much strength and assistance; but I often think that this period was as difficult on her as it was on me.

I started treatment in December, in the middle of Christmas preparations. The first step was surgery in which the doctors removed most of the tumour. The second step were five day chemotherapy sessions that made me feel lousy and nauseous all the time. The third step was radiation therapy. I had six sessions of chemotherapy with a short pause when I had radiation therapy. I can still recall the general sickness these sessions caused, and it only got worse with each treatment. I will never forget the last one that took place in July. The

sun was shining all day and all night; it being the season of the midnight sun. The heat in my room was unbearable and there was a worker with a jackhammer outside my window. I could not sleep, neither day nor night and my body had simply had enough. I paced the floor and no longer felt in control of myself. I remember on the last day of treatment the doctor did not give me my medication. He told my mother that a single day did not matter in the battle against the cancer and that my body could not take any more for now. I rarely dwell on memories from the chemotherapy sessions but come Christmas I can often smell disinfectant in the air; the same smell I found overwhelming when I started going to the hospital. I also sometimes recall those days in July when I thought I was losing my mind.



I was extremely fortunate to have good friends and everyone at my school was from the beginning both helpful and supportive. I could only attend school during the few weeks of radiation therapy; the chemo on the other hand took more time and I often had to be in isolation as I was very low in blood values. I studied as much as I could but it was often hard. The cancer caused considerable pressure on the right eye so my eyesight was very limited and the medication left me weak and tired. Luckily I had always been a diligent student so when the time came for the final exams I could take them in the hospital. I also had very good friends who came to visit frequently, supported me and cheered me on.

I also gained new friends through Icelandic Childhood Cancer Parent Organization (ICCPO). They run a very active organisation, both for the children and their families. I joined ICCPO's teenage group where I regularly met kids with similar experiences. Sometimes we discussed our conditions, but mostly we would just meet up to laugh and to forget what we were going through. When I had my health back I stayed with the group. There were always new members, and I 'm confident that they gained strength from seeing healthy and happy peers; living proof that their disease could be beaten. Through the group I also got to know about the summer camp Barretstown in Ireland, and I worked there part of the summer of 1999 and I accompanied the Icelandic group two years in a row. My work with the teenage group of ICCPO and the time in Barretstown was very rewarding. It was not until then that I truly realised how serious it is to get cancer and how lucky I was to have survived. In my work I have gotten to know many great people who have not shared my luck and have now passed away.

I finished Secondary School and then I started my training as a nurse. My experiences when I was sick and working in the camp triggered my interest in nursing; an interest which only grew through the years. I have worked extensively with adult cancer patients and even though most of them don't know about my background I have often been able to draw on my own experiences, as well as my mother's, to provide support for patients and their families. Only last week I used my experiences on the job.



Like many cancer patients I have had to face negative consequences of the cancer treatment. Soon after radiation therapy I was diagnosed with reduced activity in the pituitary gland which had also been exposed to radiation. Consequently I have needed hormonal treatments which include daily injections. With proper medication I am able to lead a normal life. When I was around 17 one of my doctors informed me and my mother that it might prove very difficult for me to ever have children. This was a bit of a shock at the time, but somehow I didn't really think that much about it at the time, I did not have a boyfriend and wasn't really considering having a family for the next few years. I focused very much on the present, probably a clever survival tool devised by my subconscious. This view of life has stayed with me and gained strength as the years go by, as I have often seen that we never know when our life is going to change. My interest in having children changed radically when I met my husband to be. Meeting him was actually one of the good results of the cancer treatment. If I hadn't gotten cancer I would not have chosen nursing as my career, and then I would not have applied for work in the old people's home where we both worked during our studies. Maybe being diagnosed with cancer wasn't all bad?

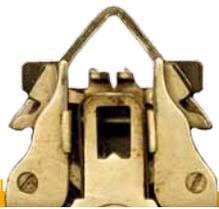
We decided together not to think too much about having children until we were ready to be responsible parents. After being a couple for four years we decided to consult doctors to see if they could help us realize our dream of having a child. The doctor said that we would just have to experiment, there were a few possibilities, but it was impossible to predict the outcome. We did not have our hopes up when we started the treatment and anticipated a long process, but then a miracle happened. I became pregnant and on 27 January 2006 we had a wonderful girl. She was both happy and healthy and we thoroughly enjoyed parenthood. It did not stop at that; we had another girl on 28 February 2008 with the help of wonderful doctors and we are thus the proud parents of two little girls today. Our dream came true!

I have to say that my life has been a good one. There have been a few obstacles along the way but with the help of good people the end result has always been positive. I do not think often about my illness but it is very easy to bring back the memories; they are not easily forgotten. This experience has made a deep and lasting impression on me, and it has made me realize that most certainly there is hope.



... I am able to lead a
normal life.





Anabella

Anabela was born in Luxembourg, where she lives with her parents. She was less than one year old when she got sick. Her mother kept a diary with comments and pictures and thus was able to tell her daughter about "her story" when she was older.

It was the 25th of April 1994, when my parents were told the diagnosis of my disease: "Ewing's Sarcoma with metastasis". I was sent to Brussels to the "Hôpital universitaire des enfants Reine Fabiola", where I got eight months of chemotherapy plus intensification. My mother could stay by my side the whole time.

Then I was prepared for bone marrow transplantation. As my mother had asthma problems she could only stay for one or two hours in the aseptic room. When she was not with me she rang the nurses and they put the telephone near my ear so I could hear her voice. I was told that I was often so sad because she was not by my side.

Finally on the 18th of February 1995, my father, my uncle and the president of the association "A heart for cancer sick children" came to pick me up and drove me home to Luxembourg. The car was decorated with balloons and people were looking at us on the highway. We kept one of the balloons as a souvenir and there is still some air left in it today. There was a big party when I came home. My brother, my sister and other family members were there to welcome me.

I regularly returned to Brussels for check-ups. At first every two weeks, then once a month and then every six months until the five years were over. In 2008 I returned to the clinic where I had an appointment with the endocrinologist. Afterwards I went to the childhood cancer unit to say hello to the professor. He was very happy to see me and explained that he had often been worried about me during the treatment.

There are some late effects I am dealing with: Probably I will be sterile. I did not get all my second teeth and the others have very thin roots. Unfortunately, the dentist cannot help me before I am 18 years old. My skin is very dry, so I need special ointment. I have problems with my big toe. So next year I have to undergo some surgery.

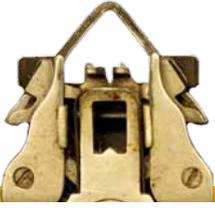
I am in a technical school and later on I want to start a career in the health care sector. I help my mother at home, have some friends to chat and I like music. I'm not worried about the future because I survived a very bad disease.

My mother had to stop working and at that time the law "break for family reason" did not exist. So my parents were very happy that there was an association taking care of us. We got financial as well as psychosocial support. Two volunteers were designated to be my godmothers. Let me take this opportunity to thank all these people who are still with us.





The car was decorated
with balloons ...



Yuumi

Yuumi lives in Japan. She was diagnosed on July 7th, 1995 at age of 7 with acute lymphoblastic leukemia. Yuumi is now 21 years old and a student at Chuo University in Tokyo. In the future, she hopes to work in a field where she can interact with children in some way.

On July 7th, 1995, I went to a hospital because I had low level temperatures and pain in my legs. I was shocked when I was admitted to the hospital right away. I thought I could be out again soon. But after three days, I was transferred to yet another hospital, the Juntendo Hospital. But then I was not so afraid any more as the nurses at the previous hospital had been very nice to me.

Before I started to get chemotherapy, the doctors explained to me everything about the treatment. It was nice that they told me what to expect using helpful drawings. They also told me that I might lose my hair when the chemotherapy started. However, the doctors never used the word “cancer” when they explained the disease to me.

Each time when I had to start a new treatment - such as x-rays - the doctors explained it to me in advance and answered any questions I had. I learned of the name of my disease on the day I was discharged from the hospital: acute lymphoblastic leukemia. The nurses there were very nice, too. They gave us patients special attention whenever we had fun events. I still treasure the gift I received from the nurses on my birthday. It is a big card with their messages written on it.

I could not go to school while I was in the hospital. Since my stay was long, I had to quit the regular school and a teacher from a special school was sent to me to the hospital. Before I changed the school, the principal, the assistant principal, and my classroom teacher had come to visit me. They brought letters that my classmates had written and the thousand cranes they had folded out of origami (colored square paper). Those friends I was especially close with came to visit me at the hospital many times and they didn't even care when my hair had fallen out.



After I came back from the hospital, I went back to my regular school. Since I was discharged in March, I went to school a day before the spring break started and greeted my friends. Our principal arranged for me to welcome in front of the whole school assembly. Because of that, I was able to go back to school wearing only a bandana instead of a wig. I spent the rest of my school years surrounded by my friends without any problem.

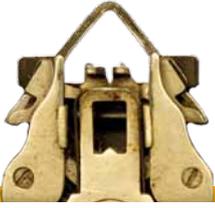
As for late effects, it was a shock to see curly hair growing instead of the straight hair I used to have. However, the happiness of having my hair back was so strong I soon recovered from the shock. Also, as the years went by, my hair became straighter, so I don't mind it now. My only worry now is that my hair is thinner and softer than before especially in the front. I am trying my best to cover it, though. My other worry is that I am chubby and don't seem to be able to lose weight. I am trying to do exercise together with my mother - without saying that she is over weight.



I am enjoying occasional invitations from the parent organization to operas and violin concerts etc. I went to summer camps and even to a camp held in America when I was a six-grader. I remember feeling much better after sharing my experiences with friends who had similar diseases.

I am a senior at a college now aiming at obtain certificates for different professions. I would like to work in a field in which I can interact with children. Since I do not think I can be a nursery or a regular school teacher, I wish to work at a toy store or at an amusement park. My other interest is working as a clerk in the medical fields since I will be able to assist patients even if indirectly. I feel envious of my father since he is working at the Bone Marrow Transplantation Foundation. I want to mention that even though I was cured without bone marrow transplant, my parents have registered at the bone marrow bank and have given theirs to other patients. I feel very proud of them.





Issam

My name is Issam. I was diagnosed in 1994 with Hodgkin's Disease. At that time I was three years old. Now I am 17 years old and hope to be a soldier to protect my country.

How precious health is! I found this out when I experienced illness and suffering at an early age. But, how can a child like me who was in 1994 only two and half years old differentiate or attribute a color, a taste or a sound to the illness, understand it and contemplate on it?

Hodgkin's Disease not only attacked my body but harshly affected my life and my parents' confidence and determination. My illness was discovered at an early stage and I was still young. I thought myself that maybe I am the youngest child who is suffering from such a disease.

I thank God who put in my way great people who cared about me. I received excellent medical care at Rabat Children's Hospital and the National Institute of Oncology where qualified doctors work and do their best.

The path towards cure took time and energy. In the same period my mother was pregnant. I never stopped thinking about my pain and the hard time my parents and I endured when I had to go to the radiotherapy center. My mother was pretending that we are going to have pictures taken. "Once in the machine, be very calm", she said. "I promise, Mom." I replied sadly without knowing anything about my fate.

Travelling from Oujda City, which is 600 km away from Rabat, was for me difficult to bear each time. But I had to get over it. Continuous check-ups, blood counts, ultrasound scans - what a long process! But with patience, the help of my parents, friends and my surroundings I overcame all my sorrows. The last week in 1994 I witnessed a happy event: the birth of my little brother! But my Dad and I did not really enjoy being with my brother until we got back from Rabat Children's Hospital.

I successfully finished my treatments. But regular check-ups started in 1995 to the end of 2007. My parents and I were so happy to hear from Dr. Nachef that I overcame my illness and that am doing pretty good.



It was such a long way that I cannot summarize in a few lines. My family and I are grateful from the depth of our hearts to those who contributed and helped in so many ways to my cure: mainly healthcare givers and those who gave us hope when we were hopeless.

Last but not least, I wish a bright future to "Maison de l'Avenir" the warm shelter, and to its volunteers who work hard to help, support and care about sick children. 



... and I was still young





Sergey

Sergey lives in Russia. My life changed forever in 1994 when I was diagnosed with non-Hodgkin's lymphoma.

As you can see I was only six years old. So I don't remember everything about my stay in hospital. But I can say that it wasn't just a surgical treatment complemented with chemotherapy. It was the best time I have ever had! All doctors knew what to tell to their patients, to support our physical, moral and psychological condition.

Afterwards I needed to continue my life outside of the hospital. I studied as much as I could but it was often hard. My Mum tells me now I had a very weak memory. And that is still the same. But I don't worry about that, because I chose the mathematical discipline as the basis, and there I can develop one formula from the other.

I finished high school, musical school and then started to study at the university. Since five years I also take part in swimming competitions where I reached the third level. My hobby is an interest in computers. It grew over the years. For me, a non-functioning computer or operating system is no problem but a challenge.



Now I study the second year at the mechanic-machine-building faculty of the national St.-Petersburg Polytechnical University. When I graduate I will be an engineer in the field of the hoisting-and-transport and road building equipment. I work as the laboratory in the State Polar Academy, my duties include management of multimedia equipment and also supporting the organization of conferences. As I already wrote above, I take a great interest in computers. Almost from any working accessories I can collect the computer. I have already collected four computers, and all of them are in use at my place.

I have to say that my life is a good one. There have been a few obstacles along the way but with the help of good people the end result has always been positive. I do not think often about my illness but it is very easy to bring back the memories; they are not easily forgotten. This experience has made a deep and lasting impression on me, and it has made me realise that there is most certainly hope.

Always be healthy and happy!







Igor

Igor lives in Serbia. He was diagnosed with ALL on November 4th, 1994. At that time he was four years old. Now Igor is 19. He is a physiotherapy student of the Secondary Medical School. He volunteers in the students' organization that organizes week-end entertainment parties for patients of the Department of Pediatric Hematology Oncology, the Hospital where he himself was treated.

At the time of my medical treatment, I was too young and I cannot clearly recollect all details relating to these days. The thing I remember the best is my Mom's smiling face and her funny stories, toys that the medical staff and friends used to give me, the pain of lumbar punctures and my one and a half year younger brother who always stayed closed to me.

I was lucky that the Hospital was in my home city so that the medical treatments could be organized through the day-care Hospital division. After therapy administration, my parents, my brother and I would go for a walk or a bicycle ride along the river banks. At times when I had to spend a couple of days in the hospital, my parents brought me a T.V. set and a V.C.R. to my hospital room, so I was watching cartoons all day long. At home, however, watching T.V. was time-limited and my younger brother was jealous because I could watch TV unrestrictedly when I was in hospital. I remember that I was taking many pills and Mom had problems since my younger brother wanted to take pills as well. The solution appeared in the form of drug-like candies.

Having completed my medical treatment, I started school and experienced no problems related to my previous condition. Ever since then, my parents participate actively in the parents' association. My Mom often appears on T.V., there are piles of publications all over the place, and all of my friends are generally acquainted with the story of my illness in my early years. It makes no problem for me and my friends do not consider my condition as anything to be discussed.

For my family, the leukemia is part of the past and the present. My parents often discuss and recollect those times. In the meantime, another brother was born (8 years younger) who is rather jealous that he had not been born at the time of my treatment. Because there are no joint photos and stories of those times to be shared with him. My parents sometimes say it appears harder to fight with our adolescence and their climax age than with my leukemia.



Considering the fact that I attend Medical School, I have learnt a lot about blood cells, drugs and the disease I used to suffer from. I often visit the hospital and play with children. Sometimes, at the sight of their hairless little heads and the intravenous injections, I pass again through all these unpleasant memories.

Still, the disease I had in my early childhood does not affect me negatively and luckily I do not experience any negative psychophysical therapy-related consequences. I completed Secondary Music School and play the piano, I attend the gym regularly; I like combat sports and do my best to practice a healthy life style. After graduation, I would like to work as a sport physiotherapist.





Barbi

My name is Barbi
I live in
South Africa.
My story begins
from when I was
10 years old. I
was in standard
2 (now known as
grade 4). 1994
was the year and
it was the same
year that I first
learnt that I
had Leukemia.

My life was turned a little upside down and I was really frustrated because I didn't know what was going on and why it was happening to me. I wasn't able to go to school for a year and had to stay at home, except for the times I had to go to the Johannesburg Hospital for my chemotherapy.

After a few months, things improved. I lost my hair after about 4-5 months of chemo and radiation. I will never forget, when I eventually chose the wig I wanted to wear – my mom wasn't too impressed: the wig I chose was dark brown, long and curly whereas my natural hair was blonde and cut into a neat bob when I first got sick. Needless to say I never wore it – instead I ended up wearing my hats mostly. It felt really strange at first but eventually got used to people looking at me in strange ways (questioningly) like they do with any person that has lost his/her hair, too.

When I think back, it was a hard and tough process – it felt like forever, but I made a lot of new friends, met amazing people, family, friends, doctors, nurses, volunteers, sports celebrities, Miss and Mr. South Africa, Reach for a Dream Foundation etc.

Thank you once again to everyone who was involved. I know that I can speak on behalf of other patients when I say you all made the days spent in the wards so much more pleasant by taking our minds off that which was happening to us at the time: by coming to visit for a few hours, playing games with us, drawing, baking, reading, competitions etc, while we were having our chemotherapy. I am not sure how it would have been without all your support.

I went back to school (Robinhills Primary in 1996) in standard 4 (Grade 6), still continuing with my chemo. I am very pleased to say that I finished my last session during that year and went into remission in Grade 7. I went on to Northcliff high school, matriculated and passed in 2002.

After high school I decided to take a gap year and went and worked as an Au-pair in America during the year of 2003. I stayed in Connecticut Au-pairing for two families during that year. I then moved to Dallas, Texas to stay with my Dad and study.



In 2004, I studied Cosmetology which is Hairdressing combined with the basics of Nails and Facial care. During 2005-2006 I worked for JC Penny as a hairdresser as well as for the same jewellery company my Dad worked for, also doing a few other part-time jobs like babysitting in between for some extra money!

At the beginning of 2006, I returned to South Africa. I was experiencing problems getting a green card in the US and had no choice but to come back. At the time I was very sad to leave. I was sad to be leaving my Dad and also some very good friends.



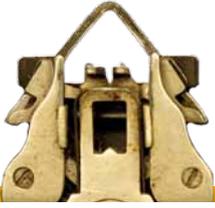
It took some time for me to settle back here in South Africa, but I can now say that I am glad to be back. I am happy working for the company where I am employed. I enjoy the people I work for (and with) – they have been very good to me.

In the meanwhile I have met my boyfriend (Julius). He is great and he is really very good to me, but most of all I am really happy to be in a relationship with someone who makes me happy.

I would like to end my story by saying a big thank-you to all my family and friends who were always there for me when I needed them. Thanks also to all the doctors, nurses and volunteers at the hospital - for all your hard work. I can honestly say from the bottom of my heart that I wouldn't have made it without any of you. All of you have had an impact on my life and have contributed to making me the person I am today.

Finally, to those of you who are going through what I went through, you and your families are in my prayers. Stay positive, best wishes and good luck to you all, may your futures be filled with lots of happiness and love always. 





Jennifer

Jennifer lives in Spain. She was diagnosed on August 22nd, 1994 with a Wilms tumour. At that time she was five. Jennifer is now a 20 year old girl and hopes to find a good job in public administration.

It all started on a warm day in August. My parents decided to take me to the local hospital because the colour of my skin had changed, I had a fever and a small lump was growing in my tummy. Doctors said that it could be a serious illness, so they sent me to Hospital La Fe in Valencia. After some tests, I was diagnosed with a Wilms' tumour. At the beginning I didn't understand anything at all. Everyone around me seemed to be afraid, sometimes crying, sometimes asking a lot of questions, they went the corridor up and down. Finally I was brought to a nice room and we could relax a little bit after this exhausting day.

I asked continuously what had happened to me, why I was there, what were they going to do to me? I was scared about being hurt and I didn't understand why doctors were carrying out so many tests on me.

"You are very ill, dear. But they're going to cure you, you'll see". This was the only answer I received from my parents. They also gave me some little books full of pictures about the treatment and about what was happening to my body. But even then, it did not take my doubts away. At this time I was too young to know the inside of my body and that was the handicap in the understanding process of my illness.

The hospital is half an hour away from home. This is a quite long but easy route and too hard to make it back and forth every day. That was the reason why my parents looked for some help to be close to me without travelling so much. The parent organisation (ASPANION) held out its hand and offered a solution. They had an apartment, very near to the hospital, with all the facilities: bedrooms, bathrooms, kitchen, etc, and of course, they gave them the support my parents needed, too.

These were not easy moments for me and for my family. I was having a bad time because my beautiful hair started falling out. I suffered from severe hearing loss and I was feeling weak and very depressed. My grandparents were overwhelmed. From my mother's side I was the second granddaughter out of five and from my father's side the only one. My uncles and aunts came to visit me. They stayed in the corridor watching me through the window. They seemed to be happy but they really had a lump in their throat, trying to smile and to control their tears. After a while, they always found an excuse to leave (they didn't want me to see them crying). My cousins were only told that I was very ill and that I needed to rest and to go to the hospital to be cured. But, there were also good days, my parents tell me a lot of anecdotes, such as: one day, just after being moved to my room from the Intensive Care Unit (ICU), doctors said that I could start drinking water or broth, but I refused because what I wanted is a sandwich. I insisted so much that nurses called the surgeon for permission. He agreed and wrote "she can eat what she wants". Some minutes later they

brought me the sandwich but I hardly had a small bite and said I didn't want any more. My parents and the doctors burst out laughing. Another funny anecdote happened on my father's birthday. I was going to be operated so he stayed with me all day. In order not to leave him alone my aunt came in the morning and my mother in the afternoon (she had to work in the morning). We had a gift for him: a pair of shoes. As I wanted to give them to him in the presence of my aunt and my mother I decided to give him one shoe in the morning and the other one in the afternoon. Now I think it was a funny idea.

While I was in the hospital I didn't want to go to school, I didn't enjoy it, so I used to read books in my room. I started reading the books for my age group and once finished I read the rest. This helped me to recover what I missed in school. In my free time, I enjoyed reading more than anything else, playing with paper dolls with my friends of the ward or with my family. I was such a loving girl that nurses, doctors and even attendants became very fond of me.

I was greatly moved when there were some parties at hospital, such as during "Fallas" when a little "falla" was put up on the terrace of the hospital and we went out dressed up as "falleros" with blouses and scarves and we sang. There was also Christmas and we saw the Kings parading while they gave us some presents. ASPANION's members always came to make us laugh when we needed and thanks to them the stay in the hospital was more fun.

The treatment was very strong, and I was admitted to hospital several times following the operations. I received chemotherapy and radiotherapy. At the beginning, the doctors thought that the tumour was a neuroblastoma, but the following tests confirmed that it was a Wilms' tumour. They started to operate on me but they realised the tumour was too big to remove. I received chemotherapy in order to reduce its size and finally they were able to take it out. They continued with radiotherapy and stronger chemotherapy until they saw I couldn't bear it any longer, and then it was reduced.



A catheter (the port-a-cath) was inserted into my body, and through it they took blood samples for blood counts and gave me the chemotherapy treatment that I needed. It is a little object made of steel and silicone placed below the skin, with a tube that goes into the veins. It doesn't bother you and it's comfortable. When my illness was stable I could return to school without any problems. With this I didn't have to put up with the pricks in my arms nor with the uncomfortable drips. It was enough to prick the silicone area and the medicine flowed into the blood.

The best day was the day that I could leave the hospital. It was so thrilling to be able to go back home - but at the same time I was afraid that I wouldn't be so well protected. I came back to be alone with my parents, to walk in the streets without receiving so much care and attention. Soon I would return to school where I hoped that everything would be normal again. Coming back home was hard but soon we got used to it, although I had new challenges: to control my urine, to walk at home, to eat heartily, to help with the house work and to feel like going out of the house.

Some time later, ASPANION gave me the possibility of going to camps with other children who, like me, have had cancer. I went every year on the trips and had a fantastic time. For a few days I enjoyed everything I saw. I went to camps in the Serra d'Ador, in Benageber, France and Girona.



The side effects of the treatment were very traumatic for this time. Due to the deafness I had to wear a hearing aid, but refused to use it out of a feeling of shame. I did not want to be "different." The loss of my hair, even though it was only temporary, embarrassed me and isolated me from other children and from people in general. I had a mild scoliosis and a scar from my navel to my side. I couldn't wear t-shirts or bikinis and it was the same story with the little scar above my breast. I got over these effects little by little, when I was fifteen and changed school; my new classmates understood my situation better, my isolation, my fears and my shame. They helped me to realise that I am not different, I am the same as everybody but with some imperfections caused by the disease. They taught me that it's better to live with some disabilities than to die. Nowadays I use the hearing aid but I have long hair and nobody sees it. And I am not ashamed to show my scars. It is no longer as important as it was years ago.

At school I received support from the teachers because I had missed the year before. So I passed the class. At first I was accepted by my classmates although they used to look at me in a strange way: it is not very usual to see a bald unsmiling girl, who is afraid of other people and who cries when she is not with her parents. I felt alone, I lived in an imaginary world for myself, I created strange characters who didn't feel bad because of their differences and I invented new friends. At that time my classmates began to insult me because of my lack of hair. They hit me because it was fun and because I didn't know how to defend myself. I had a bad time, because in the end, the teachers were also tired of my complaints. I spent some years like this, crying, feeling bad

about everything that happened to me. I didn't want to go to school and would invent any excuse to stay at home. My marks were very low, and my social life was non-existent. I was only happy when I was with my family. I received a lot of support from them. I ran to my mother's arms when I came out of school and I wished not to be separated from her ever again. Everything passed slowly and I dreamed of the day when I could feel equal to other people.

Outside of school, I had psychological support from Miss Ana Maria. She was a wonderful woman who always encouraged me to get over my fears and make new friends at school. She helped me with the different challenges that appeared from time to time. She helped me a lot to improve my behaviour at home and to help my parents, because they needed my help to go forward as well.

Afterwards I received treatment from a pedagogic psychologist, Antoni. With him I improved a little more, and he gave me new challenges. He told me that I was very clever and that if I studied hard I could be top of the class, so I began to improve, but there were still subjects I wasn't able to pass.

With the year 2004 my "scholastic pain" ended. I went to study at a small institute in the city. I met new friends, who made me feel good, I felt like any other person. I received good grades, and things changed considerably: my way of being, my friends, my marks, the way I dressed, and my hobbies. It was a change that made me happy. I was able to open up and successfully get to know new people. I met a young man one year later and he is still my partner.

My current relationships are good. My boyfriend and I are getting on very well. I am fairly demanding with friends because I am a serious person when I have to be and most of the time impetuous. I have sudden mood changes when something worries me too much and that's why I like mature people who know when to laugh and to be quiet at the right moment. I have a school friend, whom I met at the age of three, with whom I have arguments, conversations, and until very recently we didn't agree to forget the past and to start over again. I also have a friend whom I met in the internet with whom I have a very close relationship. And a neighbour that knows me since I was ill; we are almost like sisters.

In 2007 I graduated in administration and started to look for a job but I didn't find one yet. It is a difficult time to look for work in general.

When I was a child I always dreamt of being a vet, because I loved animals. But everything changed when I started to go to the vet with my pets. I didn't like watching injections or seeing wounds being healed. It was enough to fall in love with animals. I would also have liked to be a psychologist or a lawyer. Afterwards I discovered that I was very good at technical drawing which would have helped me to become an architect or a technical designer, but the studies were very difficult. Finally I dedicated myself to writing a thousand short stories and poems. I participated in competitions at school and was inspired by any place and by anything. I won some prizes, which urged me to continue writing. Now my dream is to return to university and become a writer. Writing the best stories and getting them published, becoming famous, is something which excites me.

My hobbies are quiet. I like reading and writing, chatting with my friends on the internet and posting on forums. I like sports (although I don't practice enough) such as cycling and swimming. I like to go to the gym and do gymnastics. I go out to parties from time to time with my boyfriend and other friends. I like to have a good time without going over the top. Two years ago I got my drivers' licence and bought a car on one condition: to get a job. As I haven't got one, I use the car only when visit my boyfriend or when we buy things for his flat, because he drives a motorbike.

Everything is going well in my family; there are eleven cousins and one niece on my mother's side. We love one another very much and we help each other whenever necessary. I like being with my family, most of all at Christmas; because to see my cousins happy is one of the things I like most. Having everyone together, old and young, is very lovely.

I'll never forget ASPANION. Thanks to this parent association I experience my best moments, as I said before, especially while taking part in camps. But now it's my turn to make the children who need it happy. I did the volunteers course, and since then I have done some small jobs in the parent's house, preparing Christmas presents for children who will come to stay there and for those in hospital. I would like to go to the camps as a counsellor and see the children smiling as I did.







Deniz

My name is Deniz. I live in Turkey. When I was 6 year old, I was diagnosed with Leukemia (ALL) in the summer of 1994. Now I'm 21 years old and study office management at Akdeniz University. In the future, I wish to become a CEO of a big company.

My first treatment started in a state hospital in Ankara - the capital of Turkey. I stayed in the hematology clinic for three months continuously during the intensive treatment. Later, I was discharged from the hospital and started the outpatient treatment which was done in Antalya. But every month, I had to travel from Antalya to Ankara (which is a 6 hour ride) in order to get regular medical examinations. I also received radiation therapy for 15 days. My treatment finally ended on August 20, 1997.

While all this was happening in my life, my family was having some financial problems. I have three sisters and they were all going to school. The only working person in my family was my father and it became difficult to get along on little money, since the state did not cover all the treatment expenses. In the meantime, my doctor Dr. Ustun Ezer had founded LOSEV in order to support children affected by leukemia and their families.

I realized that people are not fully aware of this disease and I think they still don't know enough about childhood leukemia. It is really depressing to be isolated because of the masks I had to wear or because my hair fell out. I lost all my friends. They were avoiding me as if I had a contagious disease. So I kept to myself and did not share my feelings and thoughts with other people just to avoid the look in their eyes, their staring at me. I stayed at home for a long time all by myself. Another problem was my education: All of my friends were going to school, when I couldn't. With the support of my family and one of our neighbors, I continued to study at home for two years. When I was able to start going back to school again, I started from second grade and then skipped third grade since I was successful. Finally, I took the university exams; and now I am in my fourth year of university studies, getting ready to graduate this year. I want to continue with my education and my academic career. This is what I concentrate on for the moment and hope to achieve.

I must say that I really owe much to LOSEV and my doctor Mr. Ezer. With their support, I completed my education in a private high school and got a scholarship for the university. I thank LOSEV for being with me and my family in every stage of my life. Otherwise, I may not have had the chance to write these lines right now.



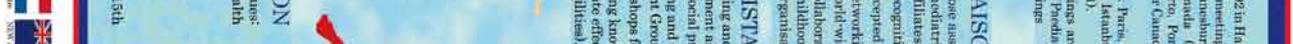
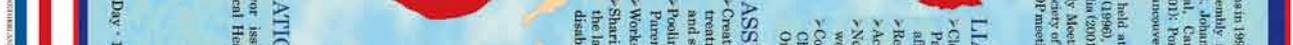
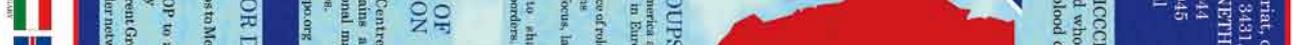
I hope all my fellow patients who are being treated in the hospital at the moment get well as soon as possible. I hope that there comes a time when no one in the world has to experience what I did; all the stages of the treatment, all the suffering and pain our family went through and the looks I got from people's eyes. I hope there comes a time when this disease is wiped out for good.





I stayed at home for a
long time all by myself.

THE INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANISATIONS

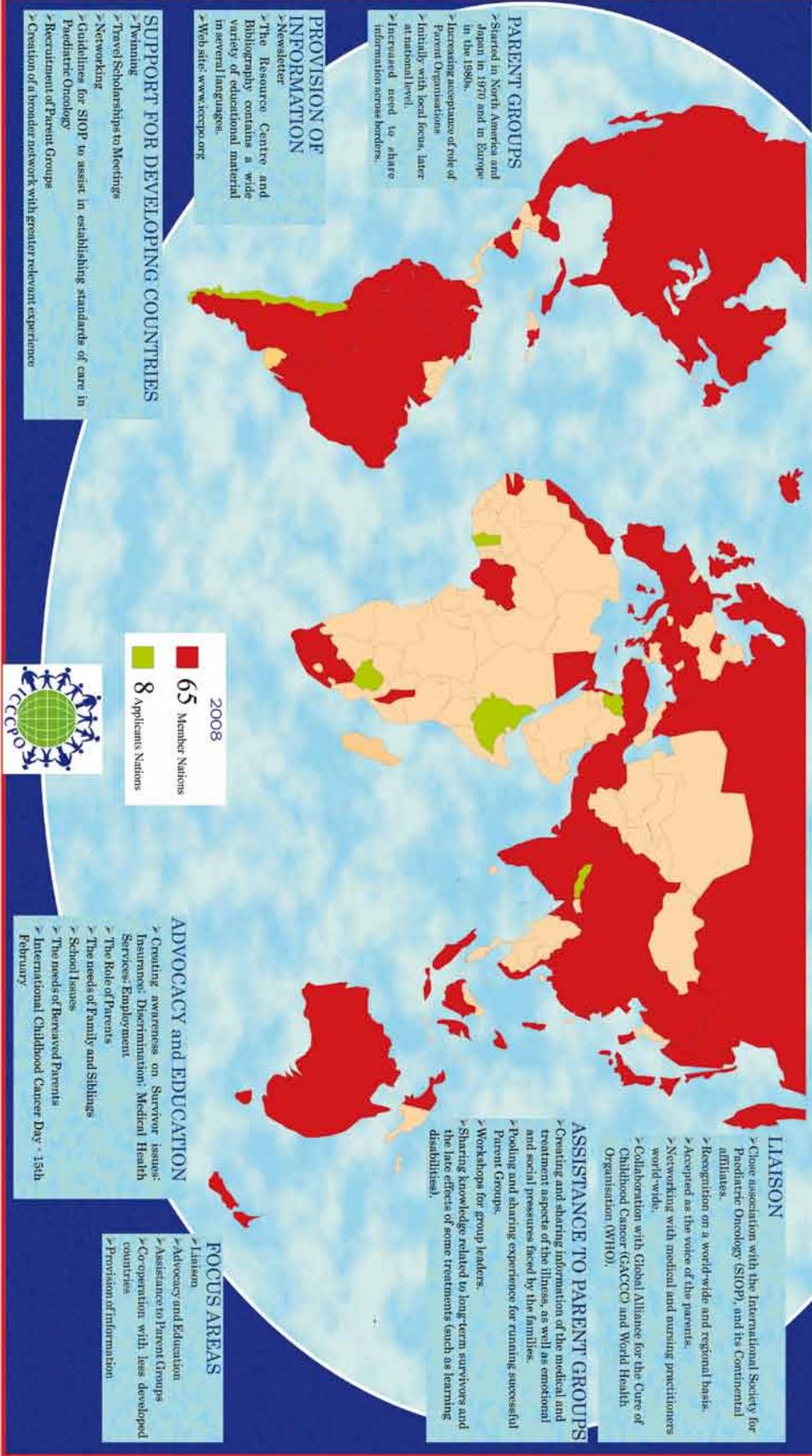


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Members of the ICCPO Board are mostly parents of a child who has had cancer or a life-threatening blood disorder. All positions are voluntary.

Sponsored by the Henk Nuijs Memorial Fund, The Netherlands

MISSION STATEMENT
To share information and experience in order to improve access to the best possible care for children with cancer everywhere in the world.



PARENT GROUPS
Started in North America and Japan in 1970 and in Europe in the 1980s.
Increasing acceptance of role of Parent Organisations
Initially with local focus, later at national level.
Increased need to share information across borders.

PROVISION OF INFORMATION
Newsletter
The Resource Centre and Bibliography contains a wide variety of educational material in several languages.
Web site: www.icccpo.org

SUPPORT FOR DEVELOPING COUNTRIES
Training
Travel Scholarships to Meetings
Networking
Guidelines for SIOP to assist in establishing standards of care in Paediatric Oncology
Recruitment of Parent Groups
Creation of a broader network with greater relevant experience

HISTORY
Initial discussions in 1992 in Hannover, founded in Valencia, Spain, May 1994.
Subsequent Assembly meetings held in Washington DC (1995), Athens, Denmark (1996), Johannesburg, South Africa (1997), Frankfurt, Germany (1998), Montreal, Canada (1999), Amsterdam, Netherlands (2000), Luxembourg (2001), Porto, Portugal (2002), Dublin, Ireland (2003), Oslo, Norway (2004), Vancouver, Canada (2005), Geneva, Switzerland (2006), Mumbai, India (2007).
Other meetings held at Paris, France (1994), Montevideo, Uruguay (1996), Vienna, Austria (1996), Istanbul, Turkey (1997), Yokohama, Japan (1998), Brisbane, Australia (2001).
Annual Assembly Meetings are usually held with the conference of SIOP (International Society of Paediatric Oncology), and ICCPO is represented at most regional SIOP meetings.

LIAISON
Close association with the International Society for Paediatric Oncology (SIOP), and its Continental affiliates.
Recognition on a world-wide and regional basis.
Accepted as the voice of the parents.
Networking with medical and nursing practitioners world-wide.
Collaboration with Global Alliance for the Cure of Childhood Cancer (GACC) and World Health Organisation (WHO).

ASSISTANCE TO PARENT GROUPS
Creating and sharing information of the medical and treatment aspects of the illness, as well as emotional and social pressures faced by the families.
Pooling and sharing experience for running successful Parent Groups.
Workshops for group leaders.
Sharing knowledge related to long-term survivors and the late effects of some treatments (such as hearing disabilities).

ADVOCACY AND EDUCATION
Creating awareness on Survivor issues: Insurance, Discrimination, Medical Health Services, Employment
The Role of Parents
The needs of Family and Siblings
School Issues
The needs of Bereaved Parents!
International Childhood Cancer Day - 15th February

FOCUS AREAS
Liaison
Advocacy and Education
Assistance to Parent Groups
Co-operation with less developed countries
Provision of information



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