niños con cáncer
Federación Española de Padres

FEDERACIÓN ESPAÑOLA
DE PADRES DE NIÑOS CON CÁNCER
C/ Monte Olivetti 18
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www.cancerinfantil.org

We care, we share ICCCPO

International Confederation
of Childhood Cancer Parent Organizations (ICCCPO)
Schouwstede 2b
3431 JB Nieuwegein
www.icccpo.org

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

GENERALITAT VALENCIANA
CONSELLERIA D'EDUCACIÓ, CULTURA I ESPORT

20th anniversary

We care, we share ICCCPO

Programme

Ceremonial act
of 20th anniversary of ICCCPO

Friday, 16 May 2014
16.30 – 17.30

Palau de Pineda
Plaza del Carmen 4 (Valencia)

Founding Ceremony of ICCCPO in 1994 (Valencia)

Welcome Messages

Jesús M.ª GONZÁLEZ MARÍN
President of Asociación de Padres de Niños
con Cáncer de la Comunidad Valenciana (ASPANION),
Former president of ICCCPO and Honorary member
Former president of Federación Española de Padres de Niños con Cáncer

Luisa BASSET SALOM
Vicepresident of ASPANION,
International Representative of Federación Española
de Padres de Niños con Cáncer, ICCCPO local organizing committee

Ceremonial Act

Kenneth DOLLMAN
ICCCPO chairman

Gabriele CALAMINUS
SIOP Immediate Past-President

Marianne NAAFS-WILSTRA
Former president of ICCCPO and Honorary Member

Pilar ORTEGA MARTÍNEZ
President of Federación Española de Padres de Niños con Cáncer

Hble. Sra. D.ª Asunción SÁNCHEZ ZAPLANA
Consellera de Bienestar Social
Regional Minister of Social Services

D.ª Susana CAMARERO BENÍTEZ
Secretaria de Estado de Servicios Sociales e Igualdad
Secretary of State for Social Services and Equality

Group picture

Jesús Mª González Marín*, president of ASPANION, Honorary member of ICCCPO, former president of ICCCPO and Federación Española de Padres de NIÑOS CON CÁNCER (FEPNC),*

Good afternoon,
H. E. Spanish Secretary of State for Social Services and Equality
Honourable Regional Minister of Social Services
Dear Friends of ICCCPO

I want to welcome you in Valencia, city which receives all of you, each 10 years, with open arms. I thank you for the huge effort you have made to be here today, and I am sorry for not speaking English and cannot communicate directly with you as I would like to do.

I bring some notes, not because of my memory, which normally fails at my age, but because I don't want to exceed the time given. It is very easy when you are talking about your life and your dreams.

None of us have chosen to have a child with cancer, but we have had the freedom to choose our dreams and to work to achieve them.

And my dreams were and still today are, to work for ensuring that all the children and adolescents with cancer receive the best treatments and have the best quality of life, them and their families. To get this challenge, in 1985, we founded ASPANION "Association of Parents of Children with Cancer", in 1990 the Spanish Federation of Childhood Cancer Parents" and in 1994 the International Confederation of Childhood Cancer Parents Organizations, ICCCPO, all of them are nowadays a wonderful reality.

Placing ourselves in the present, I think that, today, the 20th anniversary of ICCCPO, is a good day to be grateful.

I am proud and it is for me a great honor to be here to thank you for the enormous and wonderful work you have done and you continue doing, day by day, and for having succeeded in making ICCCPO as important as I never dared to dream.

My thanks also to SIOP, SEHOP and to all the medical teams for their recognition and support.

Thanks to the different government leaders for being with us today and every day.

Thanks to the organizing committee for their work and for preparing such a very special meeting.

And to all of you, my friends, my gratitude and a big hug.

Kenneth Dollman, *ICCCPO Chairman*

Birthdays are always about giving and receiving – when we are young we relish the thought of receiving and become excited about the endless possibilities to receive something special. As we grow older we relish more in the thought of giving something special to those we care deeply than about receiving. The gifts we give and receive take many forms, from the simple to the elaborate, from the unique to the ordinary, but what makes a gift special is the thought that the giver puts into the gift – the time spent thinking about what would the receiver really appreciate and value and then going out and buying this gift or creating something that is unique and one-of a kind.

Is this not exactly what happened 20 years ago when a group of individuals came together to create just such a unique gift. They drew upon personal experience, personal needs, real, raw, heartfelt emotion and put together an organization that was, and is still today – unique. They called it The International Confederation of Childhood Cancer Parent Organisations (ICCCPO) and gave it as their gift to all children and families affected by cancer in the world. ICCCPO is a gift that has never stopped giving, that has never stopped growing, that continues to care, continues to share and that makes the life of both the receiver and giver so much better and richer.

Today we are very privileged that some of those original founder members are with us to share in the joy of seeing a small organization grow into what it is today. In 1994 ICCCPO had 11 members, in 2004 ICCCPO had grown to 61 members from 52 countries – today in 2014, we have 171 members from 88 countries.

Please join me as we thank not only those who started ICCCPO, but also to the many who have taken up the challenge of growing ICCCPO into the organization it is today.

For the past 20 years ICCCPO has made the world a better place … here’s to the next 20!

Grabielle Calaminus, *SIOP Immediate Past-President*

We share a common dream ….

The success story of Pediatric Hematology and Oncology within the last 40 years is strongly linked to the commitment of parents of children suffering from cancer. The first parents groups in Europe were established in the 70ties and 80ies. At this time the first multicentre treatment protocols where introduced and it became possible to cure children with cancer. Survival rates increased quickly from almost 0% to 50%, but the needed treatment was often aggressive and toxic and supportive care structures where limited or not existing. Children with cancer where treated at regular pediatric wards, without the necessary requirements for immunedeficient patients and without sufficient staff and equipment. In addition a psychosocial support structure was lacking.

The parents suffering from the situation as their children suffered decided to fight actively to change this situation. This was the time the first parent groups were formed within European countries and elsewhere leading in 1994 to the foundation of the International Confederation of Childhood Cancer Parents organizations „ ICCCPO“ and I am proud to participate at this important day celebrating ICCCPOs 20th anniversary here in Valencia.

The commitment of parents made it possible to build up the resources in many hospitals to create Pediatric Cancer facilities and to finance enough staff with sufficient equipment. From early on the availability of an adequate psychosocial support for patients and families was in the focus of the parents initiatives. Until today parents support groups still cover part of the necessary costs to maintain the needed psychosocial care.

The role of the parent’s organization, as a political partner of the Pediatric Oncology medical community, to advocate for children with cancer is of utmost importance. Who could better share experience and explain needs than parents and their children who went through this traumatic cancer journey? So changes in political decisions regarding health policies that take childhood cancer into account are only possible with a strong alliance between parents and doctors and other care givers.

We can see that this alliance is flourishing and has already achieved major milestones:

Now in most European countries hospitals that treat children with cancer have to offer a specific standard of care covered by the public insurance system.

On the international level SIOP and ICCCPO are working together since a long time and this relation has been recently officially strengthened by signing a common “Memorandum of Understanding“ between both societies and I would like to thank here specifically Benson Pau and Kenneth Dollmann representing all active ICCCPO members worldwide, who invest their free time, their skills even their financial resources and their heart to make things better for children with cancer

SIOP and ICCCPO have also started to work hand in hand together in their relation to other important organizations such as WHO and UICC. This has led to symposia at World Cancer Leader summits, to key note lectures at SIOP meetings and recently to the launch of a signs and symptoms campaign together with UICC. I am looking forward to further common activities and I promise that I will stay active for this work in the future.

So we share the common dream that no child should die of cancer and with the commitment of all of us this dream will become true !

Pilar Ortega Martínez, *President of Federación Española de Padres de Niños Con Cáncer*

Good afternoon, H. E. Spanish Secretary of State for Social Services and Equality, Honourable Regional Minister of Social Services, President of ICCCPO. Good afternoon all our friends of ICCCPO, members of the Associations of CHILDREN WITH CANCER, of SIOP, SEHOP and the Spanish National Registry of Childhood Tumours.

It is a great honor for the Spanish Federation of Childhood Cancer Parents (**Children with Cancer**) to receive you here today to commemorate such an exciting date for us: On the 20th anniversary of the ICCCPO we are back in Valencia, where all started, to celebrate our long journey together. Congratulations to each and every one of you.

20 years ago, the love for our children with cancer moved parents from all around the World to found the ICCCPO. Today we look back and confirm how necessary it is for **Children with Cancer** in Spain and all over the World to be a part of something so important and global. Since we start together in 1994 we have been gathering and sharing experiences and we have helped and supported each other. Step by step, with optimism and confidence, the number of members has increased. Today we are 171 organizations from 88 countries in our International Confederation.

We have also seen how the concern about childhood and adolescent cancer has been growing in public institutions and medical Society. A good example is the Spanish Ministry of Health, which has shown a special sensitivity for **Children with Cancer**. In 2013, This Ministry approved significant actions for parents, such as 24 hours permanence of parents in pediatric ICUs and the extension the age for hospitalization in pediatric units up to 18. For all these reasons we are very grateful. We are also grateful with SEHOP's doctors, who are cooperating with us in different issues to improve the quality of life of our children.

Today, **Children with Cancer** embrace the whole World and through ICCCPO we arrive where we have never imagined. Under its umbrella, children and adolescents with cancer have become very important for the world. Thank you all for this great work. These children deserve everything and living is their favorite and most exciting game.

Hble. Sra. Dª Asunción Sánchez Zaplana, *Regional Minister of Social Services*

Jesús Mª González, President of ASPANION-CV, first president of ICCCPO and honorary member, **Luisa Basset**, Vice-president of ASPANION, Kenneth Dollman, President of the International Confederation of Childhood Cancer Parents Organisations, **Gabriele Calaminus**, immediate past-president of the International Society of Paediatric Oncology, , **Marianne Naafs-Wilstra**, former president of ICCCPO and honorary member, **Pilar Ortega**, president of the Spanish federation of Childhood Cancer Parents and Susana Camarero, Secretary of State for Social Services and equality. Oncology and health Professionals, representatives of the **SIOPE** and of the **Sociedad Española de Oncología y Hematología Pediátrica**, delegates of the parents' organisations, survivors and members of the International Childhood Cancer Survivors Network. Good afternoon.

It is a pleasure to participate in this historic moment, the celebration of the twentieth anniversary of the constitution of the International Confederation of Childhood Cancer Parent Organizations. It's been 20 years since the Confederation started out precisely in the city of Valencia, from the hands of 16 constituent organizations, under the leadership of the valencian president, Jesus, and in the presence of regional and local authorities.

Everyone present is aware that the most vulnerable group, without any doubt, is the minors group, although many of us know how far the youngest can teach us lessons of strength. Children are our future and we must give them our full attention, especially the most vulnerable. Childhood protection concerns us all.

Cancer doesn't know about age, gender, socioeconomic status or nationality. When the disease reaches the child, the damage extends to the whole society: to parents and then to everybody. For this reason, we can't turn our backs, we must put all resources available to alleviate the damage and help the family. Treatments, research and social support, those are the three axes in which intervention should be based.

Fortunately, there is no lack of sensitivity and support in this region. Almost 30 years ago ASPANION-Comunidad Valenciana was founded with the aim of ensuring that children with cancer and their families have the best possible quality of life. It is 25 years since the Spanish Federation of Childhood Cancer Parents was constituted, gathering and representing organizations and associations of Spain, working for children and adolescents to receive the best attention and necessary care.

Now it is the 20th anniversary of the constitution of the International Confederation, pursuing the same mission in the international area, particularly in countries with low resources where only 2 or 3 out of 10 children will survive cancer, because of the lack of well equipped and specialized units allowing an early diagnosis.

20 years later, the achievements have been adding one after another with a lot of effort. Today, more than 170 organizations from nearly 90 countries are part of the Confederation, which has managed to stand up internationally as the only voice of children and adolescents with cancer and their families. Congratulations on your anniversary, congratulations for the excellent work done during these years, and thank you, thank you very much for your outstanding contribution.

Much progress has been made, surely, but the need of continuing working remains. Hope and solidarity are fundamental, but mostly, the effort to continue improving. I encourage you to continue your work as you have done so far, and I assure you that the Generalitat (Regional Government) will also continue working on your side, with full conviction and commitment, as it always has done, to help you meet your goals.

Exma. Sra. Dª Susana Camarero Benítez, *Secretary of State for Social Services and Equality*

Good afternoon,

Firstly, I want to express, on behalf of the Ministry of Health, Social Services and Equality, to the International Confederation and the Spanish Federation of Childhood Cancer Parents, to the representatives of the Generalitat Valenciana and also to the other national and international institutions and to the people who are with us today, our satisfaction to participate in this XX Anniversary Ceremonial Act of the constitution, precisely in Valencia, of the International Confederation of Childhood Cancer Parents Organisations

I want to greet particularly Pilar Ortega, President of the Federation, with whom, from the Ministry, we have a fluent and close relationship, working together in supporting families which face the difficult and hard challenge of having a child with cancer.

This event also coincides with the commemoration of the International Day of Families and with the XX anniversary of the International Year of the Family, proclaimed by the United Nations, whose objectives and principles our Government completely share.

If there is an important institution for us, it is without any doubt, the Family. There are situations in life where the importance of the family as a source of support and affection manifests itself more strongly. The serious illness of a child is certainly one of them, perhaps the one which makes us most understand and take advantage of what the family means about support and encouragement. Because it is on the close cooperation between the medical team in the hospital and the parents where lies the essential element for the successful treatment and care of the child.

Currently, in Spain about 1,200 new cases of childhood cancer are diagnosed each year. Data show that, in our country, 80% of children with cancer under 14 will overcome their disease (higher than adult's rate). The survival rate after five years of all childhood tumors diagnosed in Spain has increased 43% in the last twenty years, reducing at the same time by 50% the risk of failure.

This hopeful evolution should not make us forget the seriousness of the issue. Neither that globally only 20% of children receive an advanced health care, while the remaining 80% live in less developed countries, where access to this type of medical care is not granted and thereby the right to the hope for a cure.

No one is free of this risk and no one can be unaware, whatever their personal situation or social condition is. Facing this reality we are obliged to get the best of ourselves, to get involved with all our strength, to be able to make that feeling of spontaneous solidarity and protection became a mechanism of support, companionship and affection.

The illness of a child not only shakes and impacts so deeply, in a personal and emotional way, but also produces the need for the family to adapt their life to deal with that reality, in work or economical aspects, among others.

All the familiar scene changes, and what was once important, what organised our time, our interest, our effort, everything is left aside, because our child, who always occupies a central place in our lives, turn for a time to be our only focus, our whole life.

These families face many challenges. Very often, they will require support from psychologists or social workers who advise them about how to make the adjustment that the family needs; and they will also need friends who have lived similar experiences.

For families the rest of their reality will continue demanding the same effort as always. World doesn't change or stop because these parents have to devote themselves almost exclusively to the care of their child or adolescent who is going through a severe situation.

This is why public authorities must work hard to make that reality easier for you, to help devote yourself to the truly essential, the only important thing, which is the care of your child. Treatment and care of childhood cancer requires not only medical care but also psychological, economical... definitely, integral support to the child and the whole family.

From the Ministry we have been supporting the Spanish Federation of Childhood Cancer Parents. It is a concrete support, sustained over the time and growing in its funding, helping in providing psychosocial and economical services, regardless of other health services belonging to different areas of the Administration.

In this line, we collaborate in the program "psychosocial and financial support for children with cancer and their families," which is intended to cover the psychological, social, emotional and economic needs of families with children with cancer.

It is a global intervention framed in the priority of "intervention for families with special needs of integral care" which seeks to identify and interpret needs and problems of each family, offering help from professionals in the different moments and situations, providing support to all the family members. Some of the actions included in this program are:

- Free accommodation in houses of the Spanish Federation, for families who need to travel for medical care.
- Free meal for the care giver of hospitalized child.
- Information and advice on the social resources.
- Free borrowing of wheelchairs, crutches and articulate beds while necessary.
- Financial help for transportation, pharmacy and other concepts.
- Psychological support for the child and the family. Support groups for parents of children with cancer.
- Educational monitoring and leisure programs.

These are only some examples of the commitment of this Ministry, turned in continuous and increasing aids, with the entities who work with families who are going through this difficult situation.
We must add other measures in the work area such as the reduced hours for parents with children with cancer which we are going to extend to parents with children in temporary foster care.
A reality included in the Comprehensive Plan for Family Support we are developing, which necessarily must include families with members with special care needs.

These examples show that the Government, the Ministry of Health, Social Services and Equality are on your side, that you are a priority in my Secretariat of State.

I insist, if supporting families is always a key objective for the Government, it is especially in the case of families which face situations like yours. We must assist, as far as possible and in the best way, these children and adolescents, and do so in a comprehensive way, covering health, social and psychological areas.

But we are in such a sensitive area, there is so much at stake, that the authorities cannot in any way act alone.

This is the reason why what the associations are doing is so important, from their own basis, from their experience, going ahead in the awareness, care, guidance, information, listening, advice ... helping one by one all who come to you, knowing what you are talking about, because you have gone through or are going through the same situation. Without forgetting that you are the channel of dialogue with the government, that collaboration and cooperation between associations and administrations is the combination needed to make everything easier and more positive.

So today I have to congratulate the ICCCPO for its twentieth anniversary, time in which it has been recognized as the only voice of children and adolescents with cancer around the world, bringing together 171 organizations from 88 countries from all the continents. It is an honour for me to participate in this celebration and also that you have chosen to come back to Valencia after twenty years. Twenty years after your work is still more necessary.

Parent groups, associations like Confederation’s members, play a vital role for the support of these children and their families. They transmitted to the public authorities their needs and through this dialogue they contribute in the design and implementation of the policies.

They are the protection and support network that allows families to focus on their primary task: to create a space of love and tenderness in which the sick children can find the strength to overcome his illness.

I would therefore insist that, from my Secretariat of State, will we will always pay attention to you. We are with you in this fight. We consider your needs, because we understand your pain. We want to walk with you to make your path easier, a path that is of all, because unfortunately today cancer strikes many families, but it shows its worst face when the patient is a child or an adolescent. And families who care them need and deserve strong support from the administration that, I repeat, we are always going to provide.

Today, I want hereby to reaffirm my acknowledgment and to express our commitment to continue working to serve the needs and demands of your families and your children. I want to transmit this commitment of the Government to the extent that such support makes easier the great role of families, which I referred to earlier as a space of trust, love, strength and hope where children find happiness they are entitled.

Thank you very much.