



## ICCCPO Chile 2013:

*Topics such as how to humanize medical attention and how to influence public policy marked the VII Latin American Conference of Organizations for Helping Children with Cancer*

The Latin American Conference of Organizaciones Sociales de Ayuda al Cáncer Infantil (Social Organizations for Helping Children with Cancer), realized for the first time in Chile, was organized by Fundación Nuestros Hijos and counted among its sponsors the **Confederación Internacional de Organizaciones de Padres de Niños con Cáncer (ICCCPO)**, **Organización Panamericana de Salud (OPS)** and **Ministerio de Salud-Chile (Minsal)**, with the objective of sharing efficient tools to better the quality of life of children worldwide diagnosed with cancer.



To receive the news that a child has cancer and managing all of the changes it causes a family is complex, even more so if the child loses his or her battle against the disease. This is what made the main presentation, by Arnaldo Pangrezzi, a professor of Camillianum at the International Institute of Sanitary Pastoral Theology in Roma, so important. He posed the importance of “humanizing medical attention”, a subject that covers relevancies on a global level and is “based on emotional competence for people who work with the patients, allowing them to handle their emotions and having a realistic vision of his or her job, understanding that the job goes beyond resolving problems; it’s also about becoming partners on this journey.”

This regional conference also included the presence of Dr. Cecilia Sepúlveda, Senior Advisor of Cancer at the World Health Organization (WHO) in Geneva, who presented a global panorama of cancer and commented that this experience has been very rich for her because at WHO they are working on public policies and, especially, in the area of children with cancer. Dr. Sepúlveda was also surprised by the organizational capabilities of the participating institutions “seeing in person how they organize themselves and unite efforts is so rewarding because it’s exactly what we’ve been promoting at WHO; how to work in an intersectorial manner and in a network to reach greater control in the prevention of this type of illness.” The doctor also highlighted the dimension of how the public can complement the work of the governments. “For the government it’s paramount because they have the immense responsibility of ensuring the population’s health and of providing adequate services, however they can’t do everything and some things have to be provided by the citizens, even more so in countries like ours where there are more limitations on the systems...I think there is great potential in this network to continue advancing in and supporting the subject of children’s cancer in Latin America.”

During the three day duration of the conference, there were various and interesting presentations, including: the vision of pediatric oncology from macro to local; the roll of the NGO’s; general knowledge about the disease (early detection, diagnostic tools and therapies); experiences in medical schools; the public benefits of the medical fields and others that affect their management; strategies of efficient governance and voluntary work; how to influence with public policies, among others. Edith Grynspalshock, a driving force behind the LATAM network and a member of the International Executive Committee, presented an initiative that seeks, long term, an alliance with Rotary and reiterated the importance of building the ICCCPO LATAM website.



Padre Arnaldo Pangrazzi  
Roma



Edith Grynspalshock  
Argentina

Dra. Cecilia Sepúlveda  
Ginebra

Dr. Julián Cárdenas, Hospital de la Cruz, Bogotá, Colombia.  
 Jazmine Fernández, Enfermería FMH, Chile.  
 Dr. Raúl Onostre, Hospital La Paz, Bolivia.  
 Leslie Ducret, Fundación Fanlyc, Panamá.  
 Dra. Cecilia Sepúlveda, Senior Adviser de Cáncer (OMS)  
 Dra. Marcela Zubieta, Directora FNH.

One of the presentations that was not met with indifference was the round table related to the “public policies of pediatric cancer and the roll of the NGO’s”.



Dr. Raul Onostre, a pediatrician from Hospital de La Paz in Bolivia, is doing an externship at the Exequiel Gonzalez Cortes Hospital in Chile because there is only one oncologist at La Paz and he feels obligated to learn and take that knowledge back to his country. Dr. Onostre dedicated 20 years to child abuse and via his perspective, convinced the government that an abused child needed to be diagnosed at medical centers. This is what he wants to achieve with childhood cancer: to be at the same level as other countries. “Currently, one of the biggest challenges we face as professionals in Bolivia is motivating health attention because only 1 in 4 children with cancer receives medical attention. In total, we are only 6 specialists because no one wants to be a pediatric oncologist. From Chile I am taking all of the knowledge and energy to change this tragic reality.”



The representative from Panama, Leslie Ducret of the Fanlyc Foundation, talked of her personal experience with cancer. Her daughter was diagnosed with cancer and survived, and that's how the foundation was born over 20 years ago. "Being here makes us see the things in our countries that we have to improve and see what level we can reach...there's a long journey ahead for the benefit of children with cancer." "Our position is that we have to improve palliative care, we have to educate more specialists and do a lot more to influence public policies in favor of children with cancer in Panama."

To this, Dr. Marcela Zubieta, director of Fundacion Nuestros Hijos and a member of the International Executive Committee of ICCCPPO, commented that Leslie is very influential in her country and asked her to work harder in preparing and engage more people so that in the future, without her, her foundation continues on this great path of fighting to improve the conditions of children with cancer "only in this way do the foundations have the possibility of surviving. On my part, I have the security that if I am not here tomorrow, Fundacion Nuestros Hijos will continue as well as it has up until this point."

Jazmine Fernández, nurse and coordinator of services for FNH, talked about the advances that exist in Chile thanks to the National Program of Antineoplastic Drugs for Children (PINDA) and insisted that "the state cannot be in charge of everything and that is why this foundation exists, to give the children all of the care and treatments that the public system cannot cover, only this way can we close the gap."

The round table discussion ended with a presentation by Dr. Julián Caballero of Fundación María José of Colombia. "In our country, during the last 5 years, they have been working on a law to integrate a child diagnosed with cancer into the system. The largest problems today are the detection of the disease and the treatments."

The VII Latin American Conference of Organizations Helping Children with Cancer counted with the assistance of the First Lady of Chile, Cecilia Morel, who, through her program, "Chose to Live Healthily", referred to the importance of promoting habits for a healthy life that contribute to lowering risk factors associated to diseases, including cancer. "Children with cancer in Chile, thanks to the excellent labor realized by our doctors, our health system and organizations are having a 75% recovery rate, but at the same time, there are 30% that have the possibility of a recurrence. The prevention with a healthy lifestyle is fundamental during this period."



Also present was the Minister of Health, Jaime Mañalich, who Fundación Nuestros Hijos works with jointly, coordinately and complementarily with the objective of reaching the best results possible for children with cancer and their families. “In Chile, a lot of the development that has occurred in medicine and public attention obeys first the initiative of foundations or of the public, which organize themselves and make an effort to help patients, especially children, through various conditions. Among them is Fundación Nuestros Hijos that, as their objective, make sure that the 500 childhood cancer cases presented in Chile each year have the best results we can offer, with high living expectations and, in the case of children that come from other regions to receive treatment, a proper place to live. In this respect, supporting Fundación Nuestros Hijos and this initiative they have organized, where over 20 international institutions from over 11 countries have come to share what they do, is very important and that is why we are here to back them.”

*Carolina Bozo  
Communications  
Fundación Nuestros Hijos*

***Final Commentaries:***

For Fundación Nuestros Hijos, this conference meant a great and beautiful challenge. Gathering the local representatives from each Latin American country to aid in the help of children with cancer was something wonderful, full of emotions and enriching experiences.

The event was grand. There were participants from NGO's from Mexico, Costa Rica, Panama, Venezuela, Colombia, Bolivia, Argentina, Ecuador, Paraguay and, of course, Chile. Peru and the Dominican Republic could not assist at the last minute due to personal issues.

The conference started with a visit to the departments of Fundación Nuestros Hijos, where we were nourished with the experiences of the parents that reside in the hospice, who were the first hosts of the event.



For many, it was the first time they were able to share with other representatives, learn of the experiences of working in other countries in the region and share emotions, dreams and desires with neighboring countries. The conference reunited a total of 128 people, maintaining an average of 100 participants daily. We counted on the presence of 45 representatives of NGO's of Latin American, 57 representatives of national NGO's, 7 hospital officials, 15 hospital school teachers and two European speakers: Dr. Cecilia Sepúlveda (WHO-Geneva) and Father Arnaldo Pangrazzi (Rome).

Over the course of three and a half days of work, the conference closed with an open forum evaluation where the participants could share their uncertainties, learning experiences and requests for future conferences with each other. The round table discussion was headed by the national representative of ICCCPPO, Dr. Marcela Zubieta, who listened to all of the opinions and promoted intersectorial work between different Latin American NGO's, while stressing the need to have more regional representatives, in such a way as to enrich the work in this field.

Exchange programs are encouraged as enriched learning experiences between different countries is a way to continue advancing the benefits for children with cancer in Latin America; in addition to generating alliances between the volunteers of different countries.

CANICA- Mexico with Javier Glavan, FANLYC- Panama with Leslie Ducret, Asociación que vivan los niños- Bolivia with Monica Mendez and GIAMALA- Costa Rica with Mariechen Lachner, were mentioned as candidates to be regional representatives of the Latin American network of ICCCPPO.

In addition, participants were invited to capture their assessments of the conference with a written evaluation. The results were completely satisfactory: 56% considered the organization of the event to be excellent while the remaining 44% evaluated it between good and very good; 54% evaluated the program as good or very good, the same as the topics presented, whereas 38% considered them to be excellent; 74% considered the clarity and quality of the presenters and speakers to be excellent and 87% evaluated the food and venue as excellent or very good. Only 3% proclaimed the geographical distance of the hotel to be a negative factor to consider.

Of the topics proposed for future conferences, in order of preference: complementary therapies, psycho-oncology and psychological support for patients and caretakers, hospices, palliative care and mourning, monitoring of survivors, work with adolescents, public policies for countries, multidisciplinary work and self-care among others.

95% of participants would recommend assisting this type of conference and the remaining 5% omitted the response.

Among the final commentaries, the one that is repeated most often is to increase the interaction of the participants, increase the debate time, increase the time for questions, create group workshops and shorten the length of the speeches. Various commented on the necessity to realize physical activity during the day, saying that 10 continuous hours of speeches a day is too much and it makes it hard to digest so much new knowledge.

It was suggested there be an agenda with the final schedule to be reviewed prior to the start of the next conference and also a report of the advances obtained through the fruit of learning and sharing at this VII Latin American Conference of ICCCP.

In conclusion, the conference was full of emotions and life, work and spiritual experiences that recharged the batteries for all that work day to day to make the road more bearable for children with cancer and their families.

*Dra. Marcela Zubieta A.  
Founder FNH y member of ICCCP*

*EU. Evelyn Vogel G.  
Nurse; Goals and Development  
Fundación Nuestros Hijos*

Presentations available at [www.fnh.cl](http://www.fnh.cl) (In Spanish):

- ***“State support for children with catastrophic illnesses or in vulnerable situations”*** (Jazmine Fernández)
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- ***“Caretaker care”*** (Rina González)
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- ***“Caretakers using art therapy”*** (Francisca Gallardo)
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- ***“The state of childhood cancer in Bolivia”*** (Dr. Raúl Onostre)
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- ***“Schools and hospital classrooms”*** (Carolina Lastreto)

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- ***“Factors that influence the process of reintegration to school”*** (Daniela Torres)
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- ***“The humanization of attention in the hospital”*** (Arnaldo Pangrazzi)
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- ***“The formation and attitude of the volunteer”*** (Arnaldo Pangrazzi)
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- ***“Erecting support networks”*** (Cecilia Prieto)
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- ***“Hospital pedagogy”*** (Silvia Riquelme, REDLACEH)
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- ***“Art therapy presentation and pediatric oncology”*** (Magdalena Illanes)
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- ***“CANICA School program”*** (María de Lourdes Álvarez)
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- ***“The roll of marketing and communication”*** (Soledad Zamorano)
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- ***“Corporate volunteers”*** (Leslie Ducret, Fanlyc)
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- ***“Cancer in children”*** (Dra. Carmen Salgado)
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- ***“The roll of clinical pharmacology in oncology”*** (QF. Claudio González)