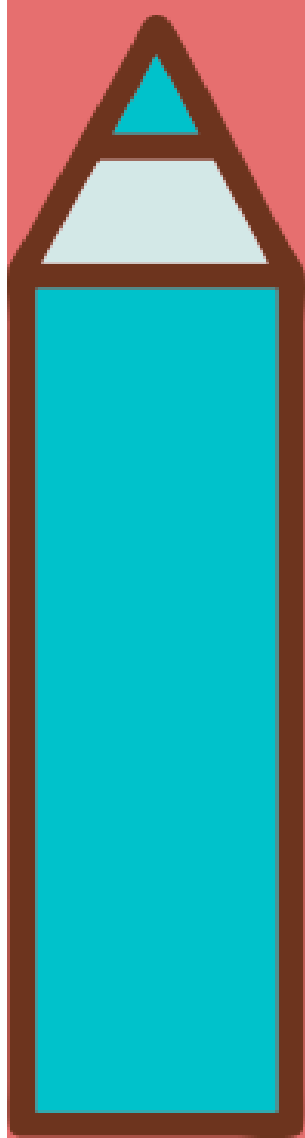




**FUNDACIÓN CENTRO SAN JUAN DE
JERUSALÉN**

**PROYECTO DE
CONVERSATORIOS
Y
CAPACITACIONES**

**QUITO- ECUADOR
2020**



FCSJJ TALKS AND TRAINING PROJECT

BACKGROUND

The San Juan de Jerusalén Foundation Center, by order of the Government of Ecuador, closed its facilities on March 16, 2020, due to the Covid-19 pandemic. This closure prompted a change of its therapeutic, psychological and pedagogical care to a virtual method.

The professionals in these areas began their work by telecare with the children and adolescents of the foundation, through video calls, video tutorials, activity documents, video guides etc. From these professionals came the idea of having talks or chats, which initially were aimed at parents, with the purpose of engaging more children in therapeutic and psychological care.

The technical areas of the foundation (therapeutic, psychological and medical areas) with the support of the pedagogical area, suggested the idea of holding a series of talks in April, not only aimed at parents, but also at education and health professionals, with the aim of becoming leaders in the therapeutic care of children and adolescents with special educational needs, associated or not with disability.

Thus, a schedule of talks were developed that would be held each week, through Zoom and Facebook live. The different topics would be set out by the multidisciplinary team (Pediatricians, Teachers, Psychologists, Physical Therapists, Occupational Therapists, and Speech Therapists); the transdisciplinary work that the foundation offers would also be demonstrated.

OBJECTIVES

- To publicize the services the San Juan de Jerusalén Foundation Center offers.
- To demonstrate the efficacy of the transdisciplinary work of the Foundation.
- To present different subjects of interest for parents of children with special educational needs associated or not with disability.
- To position and generate greater publicity for the foundation via its Facebook page.
- To organize talks and training which allow workers from the foundation to share their knowledge and experience.
- To create fundraising opportunities with the virtual talks and training project.

TALKS SCHEDULE



DATE	SUBJECTS	SPEAKERS
04/30/2020	Role of the family and the child with learning disabilities and/or disabilities	Kathy (Pediatrician) Janeth (Physical Therapist) Paul (Occupational Therapist) Jorge (Speech Therapist) David (Child Psychologist)
05/21/2020 05/28/2020	Neurofunctions in school performance.	Leslie (Occupational Therapist) William (Language Therapist) Patricia (Special Needs Educator)
06/04/2020	Pedagogical orientation in pre-school education	Patricia (Special Needs Educator) Albita (Degree in child talent development)
06/11/2020	Psychomotor activity as a therapeutic tool	Carla (Child Psychologist) Paúl (Occupational Therapist) Oscar (Physical Therapist) Jorge (Speech Therapist)
06/18/2020	Alterations in swallowing in cerebral palsy	Kathy (Pediatrician) William (Language Therapist) Janeth (Physical Therapist)
06/25/2020	Open House. We are San Juan	Carla (Child Psychologist) Paul (Occupational Therapist) Janeth (Physical Therapist) Albita (Degree in child talent development)
07/02/2020	My son, my mirror Limits, containing the crisis	Carla (Child Psychologist) David (Child Psychologist)
07/09/2020 07/16/2020	The importance of pre-school education	David (Child Psychologist) Patricia (Special Needs Educator) Albita (Degree in child talent development)
7/18/2020	A sweet adventure, parents and children	Patricia (Special Needs Educator) Albita (Degree in child talent development) Jacinta (Classroom assistant)
07/25/2020	Adventures between parents and children: A game of colors	Patricia (Special Needs Educator) Albita (Degree in child talent development) Jacinta (Classroom assistant)

FIRST TALK

SUBJECT: "The role of the family and the child with learning disabilities and/or disabilities"

DATE: April 30th 2020

AIMED AT: Parents



HOY NO LO OLVIDES

**COVID-19
ROL DE LA FAMILIA
Y EL NIÑO CON
PROBLEMAS DE**



Objectives:

- To provide information about the medical care of a child with a disability during lockdown.
- To explain interventional therapy through tele-therapy and the importance of routines.
- To guide parents on behavior management in children with or without disabilities and family behavior during lockdown.

**1. Children with disabilities and the risks from Covid-19**

Katherine Velarde, Pediatric Doctor at the Foundation, contributed by explaining the global and local health situation in the face of the Covid-19 pandemic and the risks of infection that a child with a disability may have.

Early detection of potential developmental problems or disorders can be done in a timely manner, by referring children who are born with risk factors during pregnancy or at birth, and children with genetic or hereditary disorders to therapeutic areas for intervention.

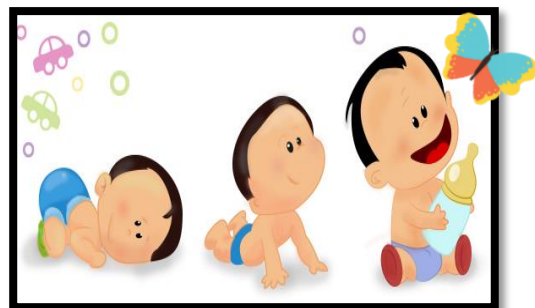


It is important to mention that a large percentage of children born with any risk factors will have learning problems at school related to reading, writing and arithmetic. This is why early support is important.

A complete physical evaluation should be carried out during the first months of life, including evaluation of spontaneous and global motor functions, oculomotor function, bucofacial motor function, psychomotor development, basic orthopedic evaluation and complementary examinations (auditory, metabolic and visual screening).

The San Juan de Jerusalén Foundation Center conducts early therapeutic evaluations and follow-ups, located at Professor Michel Le Metayer's French Neurological School.

Once the evaluation of psychomotor development has been performed, it will distinguish the child's development in the gross and fine motor areas of language and socialization. This development is controlled by the brain and is done in a sequential



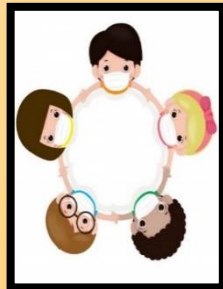
manner (first the child sits, then crawls, before reaching the walking stage).

Dr Katherine Velarde explains that physical activity and play in open spaces are basic needs of children, and constitute a right. As the children were in isolation, the foundation created supportive plans to continue therapies (physical, occupational, language and psychology therapies) and virtual classes.

This team is joined by the work of parents as facilitators, since the therapists will teach parents what their children's difficulties and skills are. They will also train parents to be a fundamental part of the therapeutic intervention process and in this way not cut or suspend therapies, as there may be setbacks in each therapist's objectives.

In addition as a Pediatrician, specific care for the child with disabilities is suggested for the reduction of Covid-19 infection:

- A high percentage of children with disability may present with respiratory problems, so prolonged use of masks is not recommended. For this reason it is advised to maintain hygiene and sanitation standards in the caregiver or family environment, wherever the child spends time.



- The caregiver should avoid leaving home wherever possible, as they can be the transmitter of the disease to their child with a disability
- Constant hand washing with the help of parents, ensuring it is done correctly or with direct assistance, depending on the motor limitation.
- Taking care and constant cleaning of orthoses at least once a day
- Frequent cleaning of surfaces, objects, toys, walkers, and wheelchairs
- Air out the rooms in the house.
- Have reserves of medications for continuous use (anticonvulsant medications), to avoid leaving the house.
- Physical activity and a balanced diet.

2. Role of physical therapy during Covid

Graduate, Janeth Dávalos, talks about her role as a physical therapist during Covid-19. She explains that education and re-education according to Michel Le Metayer: "*Are specific techniques that help us to develop to the maximum the functional motor skills of a child with a brain injury, making the best use of their potential cerebral motor function*". That is to say that for children with motor limitations, these techniques will help us to enable them to be as self-sufficient as possible and for children with motor delays, they will allow us to stimulate the baby with sensations that allow them to develop their psychomotor potential according to their stage of development.

The objectives of therapeutic education are:

- To modify pathological motor organization through appropriate techniques to improve their functional skills.
- To create situations where the child receives sensory perceptive information that they do not have due to their motor impairment.
- To offer the child the liberty to progress in their development, minimizing their difficulties and strengthening their abilities.

In the face of existing social isolation constraints, procedures have become a challenge for physical therapists, so interventions must be adapted through technology; this is why therapeutic work maintains its objectives but will focus on family support through the activities of daily living.

The involvement of the parents is an opportunity that they come to see the difficulties and abilities of their children; they will also be able to demonstrate the advances their children have had in each therapeutic session.

This is why the physical therapy intervention is done through functional objectives, through daily or family activities, these objectives support the development, the physical, social and psychological wellbeing of the child.

The functional objectives have certain characteristics, such as:

- Reflecting the family's priorities,
- Being useful and meaningful,
- Reflecting real situations,
- They can be done with several people and
- They can be measured or evaluated by yourself.



Janeth mentions that to establish physical therapy procedures, parents should be asked: What are their routines? What are their needs? How they organize their daily activities? On knowing this, the therapist will choose a daily activity and will give them a therapeutic connotation, for example: "Washing clothes" on the motor level, this activity helps to:

- Promote manual and movement abilities,
- Make motor adjustments,
- Develop balance and coordination,
- Maintain range of movement, etc.

The activities in tele-therapy will be carried out adapted to age, motor impairment and the functional objectives of each child, this is why the procedure will be done to guide and train parents to develop the skills of their children through household activities. Therapeutic work will be done through video calls, video tutorials, video guides and by sending documents with instructions.



In addition, parents of children with severe motor disabilities will be taught proper positioning techniques and orthopedic care. Due to their restriction or difficulty moving the thorax, they are prone to respiratory and digestive problems and backbone deformities; accurate positioning reduces pain and enables the child to be involved in the activities surrounding them.



Finally it is important to mention that hygiene and care for the general health and posture of the parents or carers is fundamental for the wellbeing of the disabled child.



3. How to create routines at home:

Children and adolescents also miss their routines and therefore can feel angry, distressed, irritable; but if we create a good, comfortable environment at home, we could get them to enjoy this time.

Paúl Pérez, Occupational Therapist, explains that according to the American Association of Occupational Therapy, routines are patterns of behavior that are observable, adjustable or fixed, repetitive and that give a structure to everyday life.

Occupational therapy helps children to improve the performance of daily activities; by giving them a structure, these routines can help children to improve their self-esteem and independence.

It is important to create a daily schedule to organize certain times:

- School time at home
- Housework time
- Reading time
- Play time
- Rest time



To create a routine chart, the following aspects need to be taken into account:



- Involved the child in the creation of their routines so as to stimulate their temporal, spatial and memory functions
- The function of the adult will be to write down everything the child says is part of the process of their routine.
- Then, together with the child, give a logical order to the ideas.
- Later a table or a schedule will be made and, depending on age, pictograms can be used.
- Put it in a visible place and at the right height for the child, preferably in their bedroom.



- To fulfill the objective, it is necessary to follow the routine and if a change is made, it is important to warn the child about this change.

The benefits of the creation of routines are various:

- The child will feel more autonomous and independent
- Reduce the anxiety that lockdown can cause.
- Both the child and the family will discover new skills in daily tasks.
- The child will feel happy and motivated to have a role within the family and, above all, because they will consider it a game
- Routines can be made as much to give general order to the day, as to prioritize any activity

Family support in the management of routines is an indispensable tool for controlling and reducing anxiety in children, for this reason it is important that the adult always explains what is happening and the changes that are being made in the family dynamic.

4. Language Therapy during covid-19

Jorge Castillo, the institution's Speech Therapist gives a presentation on language development and offers activities that can help parents to encourage language use in this time of isolation.

Language is a social tool which serves to communicate our ideas, desires and emotions. In the age of Covid, this communication has become restricted to the nuclear family only, which has limited children in socializing with their peers and, for that matter, restricted their primary form of learning through imitation, which affects language development.



Language stimulation should start in the earliest years of life, since this will cement subsequent language development. For this stimulation, the child needs to feel motivated and participate in the communication situation to additionally favor the development of cognitive and affective structures.

Jorge mentions that it is important to understand a child's language development from the pre-linguistic stage through adolescence, with the goal that parents would be able to identify whether their children are exhibiting age-appropriate language development, or if they present with a delay.







He also explains the most common errors parents make that may limit their child's communication skills, such as, for example, changing the names of things or indicating



objects by pointing and without making sounds or naming the object.

Language stimulation should be done in an age-appropriate way for the child, through affection and play, for example:

<p>- 0-3 months:</p> <ul style="list-style-type: none"> ○ use maternal language: high-pitched and melodic tone. ○ visual contact. ○ simple phrases. 		<p>- 1 year:</p> <ul style="list-style-type: none"> ○ chewing solid foods, which improves the development of the orofacial musculature
<p>- 4-6 months:</p> <ul style="list-style-type: none"> ○ answer their vocalisations and sounds, ○ sing to them when they are calm ○ make exaggerated gestures to stimulate reactions 		<p>- 2 years:</p> <ul style="list-style-type: none"> ○ more varied vocabulary, ○ listen without pressuring them, don't interrupt them
<p>- 7-9 months:</p> <ul style="list-style-type: none"> ○ reply to their babbling, ○ talk to them about everyday objects and nearby sounds, ○ tell them age-appropriate stories 		<p>- 3 Years:</p> <ul style="list-style-type: none"> ○ play memory games
<p>- 10- 12 months:</p> <ul style="list-style-type: none"> ○ play with musical instruments, ○ say the name of objects correctly, ask them to imitate 		<p>- 4 years:</p> <ul style="list-style-type: none"> ○ play guessing games, like "say a word which begins with pa..."
		<p>- 5 years:</p> <ul style="list-style-type: none"> ○ play with puppets, answer questions and concerns
		<p>- 6 years and up:</p> <ul style="list-style-type: none"> ○ practice tongue twisters, stories

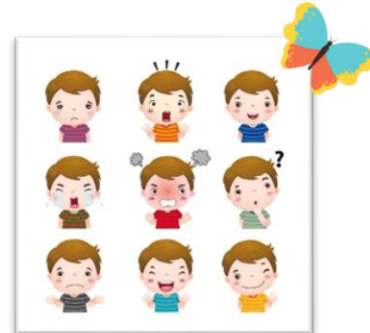
Finally, he mentions that nowadays, children have greater access time to tablets and computers, but it is recommended that the parents don't leave the child alone with these. Instead, use this time as a guide, stimulating their language skills through apps, songs, videos or games, and that this time should be productive time for the child.

5. Anxiety management for parents and children

Child psychologist and psychological rehabilitation specialist David Díaz talked to parents about how to stay calm during quarantine, since it is normal in this situation to feel more scared than usual and to have questions about health, economic stability, and their children's studies and therapy, among other things.

Parents have significant difficulties in expressing their feelings of fear, and when getting questions about their children's fears, parents usually respond that everything is okay. The child hears this response, but understand that this isn't the case.

It is very common for children at home to begin to display irritable behavior and be upset. In the majority of cases, it is a reflection of their parent's unease with the situation. This can be seen more obviously through inadequate progress in their academic activities or their therapies.



When a child with a disability in which motor function is affected experiences negative emotions, the child begins demonstrate greater spasticity, greater difficulty in the execution of movements which they were already carrying out, and they will become more rigid, to the point of causing physical pain.

In children with learning difficulties or ADHD, it is observed that fear causes more anxiety, irritability, and sadness. With regard to learning, there are also problems with learning consolidation, as well as difficulties in paying attention and understanding.

David suggests different alternatives to reduce anxiety for children and their families, such as:



- It is important to establish a routine based on their new schedules, where time for studying, eating, leisure, and play are included
- Organized space for virtual classes or teletherapy



- It is important that spaces set aside for playing and sports are motivating or interesting for the child
- Avoid providing too much information about Covid. Verify that it is true, and give it to the family an appropriate way.
- Establish leisure time and off-line time that you can share as a couple or with your children.

The importance of supporting roles for teletherapy professionals is going to be crucial in the therapeutic process for young people with educational needs whether or not they are associated with a disability.

- The therapist is going to provide their teletherapy service through a tablet, a computer, or a cell phone.
- The child will be the central focus, in other words, depending on their age, the child may be able to establish a direct connection with their therapist.
- If this is not possible, the parents will be trained by the therapists to carry out the activities at home, directed to comply with the therapeutic objectives of each professional in the different areas.
- Another alternative is teletherapy with the child and the support of their parents during that time. The therapist will continue guiding the parent in real time on how to carry out the activity with their child.

An important aspect for the well-being of children at home is to consistently maintain socialization with children their own age or their friends. This space should be respected by the parents, fostering their child's communications with people or children outside of the family environment.

At the end of the activities, the participants have approximately 30 minutes to ask the professionals questions. These concerns come mostly from the parents of the families, but educational and health professionals also participate.

With this experience, the themes and content of subsequent conversations will be adapted with information for both the parents and the professionals.





Gracias por participar en nuestro conversatorio.



#TodosSomosSanJuan