

## FUNDACIÓN CENTRO SAN JUAN DE JERUSALÉN

# CASA ABIERTA VIRTUAL NOSOTROS SOMOS SAN JUAN

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QUITO - ECUADOR

2020

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### SIXTH ROUND TABLE

TOPIC: "Virtual open house: We are San Juan"

DATE: Thursday, June 25, 2020

#### TARGET AUDIENCE: General public

#### **Objectives:**

- 1. Provide information about the services that the San Juan de Jerusalén Foundation offers.
- 2. Visually present the activities that are carried out in each of the Foundation's departments.
- 3. Show the institutional organization and physical spaces.
- 4. Showcase the interdisciplinary, comprehensive and inclusive work that the Foundation does.



#### 1. Introduction





A secular Ecuadorian non-profit NGO located in the city of Quito, we have 34 years of specialist experience in the comprehensive care of children and adolescents aged between 0 and 18 who have neurodevelopment disorders, cerebral palsy, transient developmental problems, and socio-emotional and behavioral difficulties.

With the dream of our children attaining genuine and high-quality inclusion in their family, school and community environments, we aim to fully develop the strengths of the children and their families. We use a humanistic approach that sees the child as an indivisible being and involves an interdisciplinary team, parents and teachers in an experience-based, educational, therapeutic and emotional process.







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We are located at Pasaje Jerónimo Carrión and Enrique Ritter, in Miraflores, diagonally across from the Universidad Central tennis courts.

Our institution is made up of:

- Administrative Board: composed of 6 members
- Administrative department
- Fundraising department
- Accounting department
- Services department
- Coordination unit
- Teaching department
- Therapeutic department: physical therapy, speech therapy, occupational therapy and psychology
- Early diagnosis department 0

To improve a child or adolescent's quality of life in the school, social and family environments, we have a highly trained interdisciplinary team that works using a rightsbased approach with humanistic, inclusive and comprehensive principles.

The Foundation has the following facilities:

























#### 2. Teaching Department

The teaching department has two spaces: the early learning classroom and the comprehensive development space. We do interdisciplinary work, i.e. working alongside the therapeutic departments (physical therapy, speech therapy, occupational therapy and psychology).

The creation of these spaces makes it possible to boost the child's quality of life, which is underpinned by comprehensive care management, thus enabling cognitive, socio-emotional, psychomotor, speech and family development. In this project, teaching objectives are delivered against the backdrop of inclusive education, with warmth and good quality management.









Using a reverse inclusion model, the San Juan de Jerusalén Foundation aims to promote and work in an environment where mainstream children integrate and socialize with children with disabilities, and to raise awareness among children and families. Our approach is comprehensive, as it considers the child as a whole by seeing the intellect in their head, the socio-active aspect in their heart and the motor part in their hands and feet.

During the greeting, the child can express their emotions and feelings, i.e. they can say if they are happy or sad. Also, at the beginning of the day, the teachers write the date, check attendance with children's help, and sometimes explain to them why one of their classmates is away. All of the children are participants in this activity. Children with disabilities and difficulties with oral expression use a bespoke communication board, designed by the speech therapy department to aid communication by respecting each child's needs and strengthening their abilities.





Including mainstream children in an environment of children with disabilities from an early age helps us to foster core values like respect, solidarity and empathy, in an environment of respect for diversity. Teaching activities are adapted to the needs of each child and the necessary resources sought, so that all of the children can do the activities set by the teachers on equal terms. Similarly, all of the children enjoy themselves, are motivated and are part of the fun in the play space at recess.











Learning is mainly based on experiences and recreational projects that enable the children to express their happiness, motivation and curiosity by discovering and exploring their environment. In addition, all of the children participate in Ecuador's social and cultural events, such as the Fiestas de Quito and Carnival. These activities are run and supported by the Foundation's staff to provide support and security for all of the children.



The festivities are taught through experiencebased participation using bodily experience. For example, during Carnival, the children got to design their costumes themselves, using various art and craft techniques such as painting and gluing, and then enjoyed the celebration.

We have an excellent physical space for appropriate learning, with a series of adaptations, orthoses and technical aids that enable children with disabilities and with motor disorders to have body stability and a better field of vision, and also enable them to handle materials better to interact with their peers. These adaptations and technical aids are:

- o hip spicas
- o molded plaster chairs
- o polypropylene chairs
- o molded foam chairs
- o tables with cutouts and tilted tabletops



#### Educational outings and camps

Educational outings are teaching strategies that foster the understanding of skills in a more experience-based and dynamic manner. The objective of the camps is for children to speak confidently, strengthen emotional ties with their peers and have new experiences outside of the family setting that help to build confidence. In this way, we









aim for everyone to achieve their small goals or dreams, which sometimes seem impossible or unlikely but can become a reality by joining forces.



#### 3. Psychology Department

#### Assessments

The psychology department carries out the following assessments:



- **Developmental assessment:** This simple assessment is carried out on children aged between 6 months and 2 years and 6 months, using the Brunet-Lèzine psychomotor development scale. It assesses the four key areas of development (posture, coordination, speech and sociability), and allows the assessor to spend time with the child and their family. The child is then referred to the different therapeutic departments (speech therapy, physical therapy, occupational therapy and psychology).

**Cognitive, emotional and psychopedagogical assessments**: These assessments are performed on children aged 2 years and 7 months to 17 years and 9 months. Depending on the age, the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) or the Wechsler Intelligence Scale for Children (WISC) may be used. These tests help us to assess the child or adolescent's verbal comprehension, visual spatial abilities, fluid reasoning, working memory and processing speed.











On the basis of the assessment results, a report is produced to inform the family of which areas the child and/or the family need to work on. The report also identifies needs concerning therapy, educational inclusion support and curriculum adaptation.

#### Psychological treatment

If the child, adolescent or family needs psychological intervention, the psychology department can offer them either individual or group psychotherapy.

- **Individual psychotherapy:** The psychologist works directly with the child or with the child and their parent.
- **Group psychotherapy:** The psychologist works with children of the same age.

By its very nature, emotional work requires a safe environment. The child or adolescent needs to feel safe to tell the psychologist how they are truly feeling or what they are going through. In addition, the psychologist will address behavior through speaking and playing in certain environments using routines.



✤ Groups



**Psychomotor education groups:** This comprehensive work is carried jointly with the teaching department to develop the children's body awareness and respect for themselves and others. The children in the class are aged 1 year and 3 months to 5 years, and the groups have no more than five or six children.

The groups use a speech area, where the child can express their feelings and emotions, and a play area, where the psychologist uses goal-setting to mediate and guide the children to behave appropriately and get on with their peers.









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Expression workshops: These are aimed at children and adolescents aged 5 to 15 years and are split by age group into young children, older children and adolescents. Like the psychomotor education groups, they also use a speech area and an activity area. At the end of the expression workshops, experience-based camps are held in which children with and without disabilities develop independence, responsibility, autonomy and the ability to get along with others.





Inclusive education





The psychology department monitors the child or adolescent's educational achievement and communicates with tutors, with the Foundation's management team or the student counselling department, and with the child's classmates.

In the first meeting, the therapist explains the child or adolescent's medical condition and suggests to the teachers activities or alternatives methods for working with children who have special educational needs related or unrelated to disability. In addition, depending on the case, the school program is adapted, and the therapists' work within the Foundation is explained to the teachers so that all concerned can work in a transdisciplinary and comprehensive manner to meet all the child's needs and ensure their appropriate social and educational inclusion. Likewise, we support the inclusive education of the children who attend our classes at the Foundation.









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#### 4. Physical Therapy

#### ✤ Early intervention

The purpose of early intervention is to guide the baby in their first motor experiences and to develop their innate brain motor resources to generate movements that are as normal as possible. To that end, the newborn's innate potential must be assessed by exposing the child to complex physical situations to which they must automatically adapt. This assessment allows us to determine whether the disorder is transient or permanent.



#### ••• Motor or neuromotor re-education



✤ Aims of therapeutic education

orthopedic level.

Motor or neuromotor re-education refers to all the corrections made during the execution of movements. In children with motor disorders who have acquired motor habits by themselves through voluntary efforts, those habits partially limit their potential, and these compensations risk becoming complications, especially at an

- To fully develop the child's functional motor skills in accordance with the severity 0 of motor disorder.
- o To create situations in which the child can receive the sensory perceptual information that they lack.
- To offer the child freedom in their development by minimizing the effects of their impairment and furthering their potential.

We have countless therapeutic tools to achieve these objectives, for example:

Psychomotor circuits: To work on 0 balance, walking, pulling, crawling, etc.



















Climbing wall: To work strength, coordination, balance and postural control, and in the case of severe motor disorders, even to relax the body by means of suspension.

• TheraSuit method: A specific technique that helps to improve posture and reduce incorrect trunk positions and enables better control and ability in motor activities.





Treatment for children with severe disorders

In these cases, the therapist's work involves applying relaxation maneuvers, preserving the range of joint movement and providing sensory motor experiences that the child lacks because of their motor limitation. The therapist uses all the necessary resources to accomplish this goal; for example, balls, a treadmill with a securing harness, walkers with securing elements, etc.











Orthopedic treatment





The need for a bespoke orthopedic device is jointly assessed with the occupational therapy department. The device will improve the child or adolescent's quality of life, not only in terms of their orthopedic care, but also their educational and social inclusion. The following adaptations are made by the Foundation's physical therapy department and occupational therapy department:

- Ankle-foot orthoses
- Hip spicas
- Molded plaster chairs
- o Molded foam chairs











In view of lockdown restrictions during the COVID-19 pandemic, our physiotherapists searched for alternatives means to continue treating the children under the Foundation's care. Using teletherapy (therapy by video), they were able to teach parents to do different activities. They have also used other tools, such as videos, photos, presentations, model therapy (use of dolls), to teach the families about physical therapy management and intervention at home.







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#### 5. Occupational Therapy

The role of the occupational therapist is to support the child as they mature, in order to improve their abilities and skills in everyday activities.

Forming part of pediatric neurorehabilitation, occupational therapy uses play to develop the child's skills and abilities, stimulate independence in daily activities and promote learning through sensory stimulation from an early age.

#### ✤ Areas of intervention

**Manipulative development:** Upper limb functionality, which is important in developing fine motor skills, is assessed. The child needs to be able to demonstrate adequate grasping, pinching, antigravity movements and individual movements of upper limb segments.





**Perceptual-cognitive development:** The children develop skills and abilities throughout the preschool stage. Through perceptual-cognitive activity, the child gains an understanding of gravity and, by exploring, learns to discriminate and recognize objects or shapes through tactile and visual means.

**Ocular motor skills:** Our occupational therapy department was the first in Ecuador to set up a dark room, which is used to stimulate ocular motor skills and visual strategies 'fixation, tracking, visual exploration, visual field). Given the importance of these key ocular motor strategies in reading and writing acquisition, they can start to be trained or stimulated from the age of one month. In addition, in children who have gaze strategy impairment, strabismus or nystagmus, intervention involves ocular motor reeducation.









**Everyday activities:** Intervention addresses the skills need to perform activities such as dressing, undressing, feeding and maintaining personal hygiene, taking into consideration the developmental milestones for the child's age. The aim is for the child to gain independence and autonomy.





- **Executive functions:** Stimulation, education, and re-education of higher mental functions such as attention, memory, reasoning, planning, abstraction, etc.
- Learning difficulties: Intervention for specific learning difficulties and disorders (reading, writing and numeracy).

#### Therapeutic groups

**Sensory-motor group:** This group is composed of children aged from 1 year and 6 months to 3 years. Bodily learning experience is stimulated through the senses, using physical resources such as the dark room and the climbing wall.











**Preschool group:** This group is composed of children aged from 3 to 5 years. It aims to stimulate the acquisition of basic neurofunctions for reading, writing and numeracy, through activities to develop fine motor skills, rhythm, spatial and temporal orientation, pre-math skills (classification, seriation, the idea of number and quantity) and pre-writing skills.







Group activities are led by the occupational therapists, who are supported by the teachers, and all the children participate in the activities. The adult helps the children with disabilities to perform the movements and provides them personal support so that they can understand and learn to do the activity.

#### Technical and orthotic aids

The occupational therapy department provides various technical or orthotic aids to improve the quality of the child's grip in various everyday activities, such as:









- o Grips for writing instruments
- Adapted feeding instruments
- o Hand splints
- Furniture adaptation assessments for furniture used in learning.





#### 6. Speech Therapy

Speech therapy is a health discipline concerned with preventing, assessing, diagnosing, educating and rehabilitating patients with disorders related to communication, hearing and swallowing. The work is focused on rehabilitating and conveying information to children who, because of their particular characteristics, may not be developing in accordance with their chronological age.

The speech therapy department works with different materials and tools, such as:



- Computers: On the computer, we show images, ask the children questions, convey information, explain concepts, etc., to aid continued speech development.
- Traditional physical tools: These include stories, which help to train reading fluency, and phonological awareness activities. All of these influence the subsequent development of the children's communication skills and their learning.











The speech therapy department of the San Juan de Jerusalén Foundation specializes in helping children with neurodevelopmental disorders, such as intellectual disability and autism, and speech and language problems such as articulation disorders and phonetic-phonological disorders, and provides care to children with cerebral palsy. We aim to stimulate, encourage, educate and rehabilitate the children's communication and to convey information in a playful, experience-based and humanistic manner. Like all the other departments, we seek ways for children with disabilities and mainstream children to do the same activities.



#### Therapeutic intervention



- Individual therapy: Individual therapy involves the following:
- Assessment: The child's language abilities are identified through tests.
- Intervention: A treatment plan is prepared in accordance with the assessment results. The games and activities are playful, fun and ageappropriate.
- **Group therapies:** These aim to stimulate children's communication skills through interaction with their peers, parents or therapists, who are the communication facilitators. The children get to explore and have fun.



#### Intervention techniques

The main teaching means is play, since it motivates the child and gets them to engage in the activity in a more productive way for their therapeutic process. In addition, the department has technical resources specialized exclusively in speech and language therapy, such as electrical stimulators and low-level-laser therapy.















#### 7. Medical Department

#### Early diagnosis program



The family's support during the therapeutic process is also essential because the family environment is where the child spends the most time, and that support enables the child to interact better with the people who they trust the most.

We can also stimulate language by using puppets. This activity allows us to develop our creativity as adults while stimulating the children's expression of their emotions and communicative intentions.

Our work at the Foundation includes not only the practice of pediatrics but also the early diagnosis of neurodevelopmental motor disorders. That is why we always assess those children where there is a history of risk factors during the pregnancy and in the first months and years of life, to carry out timely and early therapeutic intervention for better development of the child.

#### Medical history: risk factors

- Pre- and perinatal:
  - o Vaginal bleeding
  - o Twin pregnancy
  - o Preeclampsia
  - o Maternal alcohol use
  - o Premature birth









- o Weight
- o Hyperbilirubinemia (neonatal jaundice)
- Hypoglycemia/sepsis/convulsions
- o Intraventricular hemorrhage

The above factors, whether present individually and in succession or as several simultaneously, generally constitutes a risk factor for motor or neurological disorders. Other factors can include genetic, epigenetic and environmental factors.

When taking the history, it is important to ask the parents about: family medical history; speech disorders; difficulties in reading, writing and mathematics; stillbirths; and epilepsy.

The practitioner should inquire about other risk factors, including previous diseases, traumatic brain injuries and diagnosed hypothyroidism, and should check that the vaccination card is up to date for the child's age. In addition, the child should undergo hearing and metabolic screening and, in the case of premature children, screening of the back of the eye.

#### Neurodevelopmental profile



Physical examination

The achievement of psychomotor developmental milestones from birth and through infancy, childhood, puberty and adolescence should be investigated. The practitioner will ask about the beginning of the history of learning difficulties; how problems previously and currently manifest; the effects on academic, family and social functioning; and school reports, to gauge academic skills and achievements.

- Body measurement: Weight, height and head circumference are measured in relation to the child's age and sex.
- Pediatric physical examination using apparatuses and systems: The child's skull, skin, muscle strength and tone, reflexes and phenotypic alterations are checked.
- Basic orthopedic assessment
- Assessment of oculomotor and orofacial motor skills
- Verification of the assessment of retinopathy of prematurity
- Assessment of possible neuromotor disorders: Using the assessment designed by the French neurological school of Professor Michel Le Métayer, we perform specific techniques to provoke motor responses to determine the existence of pathological motor factors. The following assessments are carried out:
  - o Assessment of spontaneous motor skills
  - o Global motor assessment















#### Regular pediatric assessments

The children who attend our Foundation receive medical follow-up, regardless of whether they are our class children or external children. This is complemented with an assessment of the child's nutritional condition, the detection and treatment of infectious childhood diseases, immunization and neurodevelopmental assessment.

The aim of these assessments is to ensure timely referral for transdisciplinary intervention by the team of professionals in the therapeutic department. The team consists of:

- Physical, occupational and speech therapists
- o A psychologist to support the child
- o A psychologist to support the family
- o Teachers/kindergarten assistants



Therapeutic intervention is based on neurodevelopmental assessment, so each gammer motor control, cognitive development, language and sociability leads to the achievement of the developmental milestones that follow hierarchically. Therapeutic intervention needs to start early, in order to take advantage of the potential of the child's brain plasticity. Therefore, if a child presents the above-mentioned risk factors at birth, the intervention can be performed from birth.

Moreover, professionals need to have knowledge of biomechanics, muscle re-education and abnormal reflex activity, to fully develop each child's motor potential.











Possible disorders affecting specific academic skills in the areas of reading, writing or mathematics should be identified early. In addition, the achievements and difficulties in the intervention process should be regularly evaluated, and techniques and methods constantly reconsidered if necessary.

At the Foundation, we use an individual treatment plan (ITP), whereby the professionals from each department who are involved with a child analyze, in a group, the assessments and treatments that they have carried out and propose specific, transdisciplinary work objectives. This activity takes place every six months and the plan is shared with the parents.

#### 8. Closure of the Virtual Open House

This work would not be possible without a team of committed and creative professionals who are passionate about what they do, and we are grateful to them. Each child's achievement fills our souls with infinite joy and satisfaction.

#### Our supporters

Financial support for the Foundation is also vital for us to be able to do all this work. We receive financial input through:

- o self-management
- support from the parents
- international organizations: Partage, Pan Contra el Hambre and Asociación Tierra Fraterna



This support covers 70% of our annual budget, leaving a deficit of 30%. For eight years we had a technical and scientific cooperation agreement with the Ministry of Public Health, through the Isidro Ayora Obstetrics and Gynecology Hospital. However, this agreement, which related to the early detection of neurodevelopmental disorders, ended in 2018.









As a result, more than 1,300 newborns with risk factors, who were receiving around 7,200 specialty care contacts annually, were left without care. In addition, the impact on our budget meant that we had to make two health professionals, an administrative staff member and a service staff member redundant.

To somehow cover this deficit, we developed several projects through our fundraising department, including community engagement projects, training and a sponsorship plan, but it was not enough.

We are calling on the community to help our children, adolescents and families. In addition to their difficult economic situations and the current crisis, they are also living with a disability that involves permanent, long-term treatments, entailing high and unsustainable costs. Every penny supports our efforts, allowing us to provide good quality care delivered with warmth. So we invite you to show solidarity with our project. Get in touch and we will provide details on how you can help.











