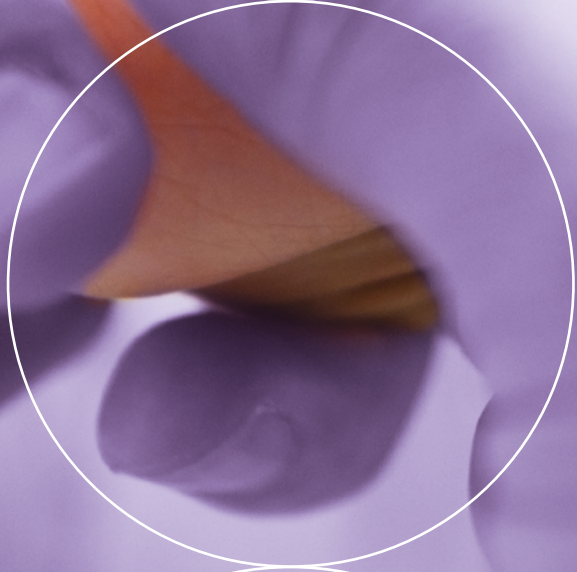
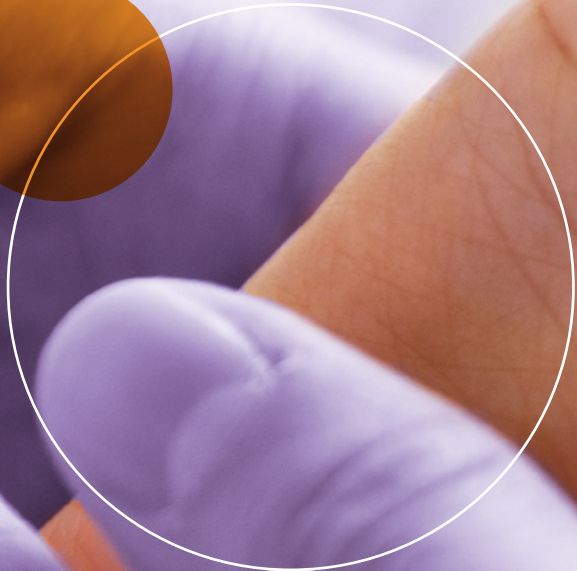
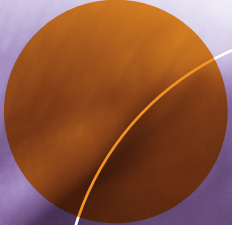
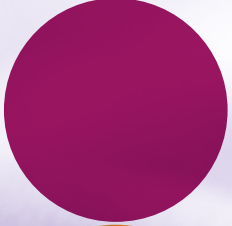
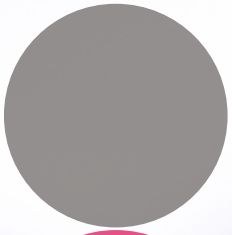


HEALTH



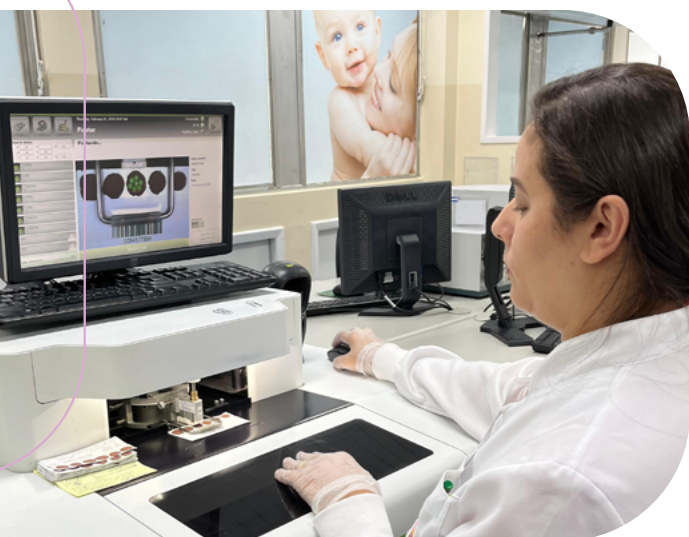
/// NEWBORN SCREENING TEST



Pioneers for over four decades: professionalism, dedication, and innovation in Neonatal Health.

Neonatal screening is a set of tests designed to detect a variety of health conditions in newborns. Among these is the Newborn Screening Test—commonly known as the Heel Prick Test—which involves collecting drops of blood from the baby’s heel, ideally between 48 hours and the 5th day after birth. This test can detect around 50 different diseases.

It helps identify genetic, metabolic, immunological, and infectious conditions that, if left untreated, may lead to Intellectual Disability, loss of mobility, weakened immunity, or even death. The Instituto Jô Clemente (IJC) performs this test using a broad panel of screenings, applying advanced methodologies and techniques to ensure accurate and reliable diagnoses.



Blood sample collection from the baby’s heel on filter paper.

We are a Reference Center for Neonatal Screening, accredited since 2001 by the Ministry of Health. IJC performs the Newborn Screening Test for 100% of babies born within the public health system of the city of São Paulo (via SUS) and for 68% of those born in both public and private systems throughout the state of São Paulo. We also offer private services.



Perforation: small dots are made in the filter paper to extract the blood sample.



of babies born in
the public and private health systems of the state of São Paulo



of babies born in the
public health system of the city of São Paulo

* Pioneers: the first people to do something new, paving the way for others.



1



Information and Awareness

The **Newborn Screening Test is a right guaranteed by law** (Law 10.889/2001), which makes it mandatory and free for all newborns across Brazil. To ensure that children diagnosed through the test receive effective treatment, it is essential that families receive a prompt diagnosis and clear guidance on the next steps needed to continue appropriate care.

2



Family Engagement*

At the Instituto Jô Clemente (IJC), we recognize the fundamental role families play in the success of treatment. That's why family engagement is one of our Strategic Guidelines for 2025–2027. We develop educational materials, such as booklets and videos shown in waiting rooms, and we promote awareness through campaigns like Lilac June, aimed at increasing access to information about the Newborn Screening Test.

3



Active Search to Ensure Treatment

When the Newborn Screening Test indicates potential abnormalities, our Active Search team works to locate the baby's family, provide guidance, and refer them for further testing or specialist consultations, ensuring treatment starts as early as possible.

4



Training of Health Professionals*

We train healthcare professionals who work in maternity wards, hospitals, primary care units, clinics, and other facilities to ensure proper blood collection for the Newborn Screening Test. This has helped reduce collection errors by over 7%. Proper collection, storage, and transportation of blood samples must follow strict quality standards to guarantee safe and timely results.

To support this, we offer in-person and online training, as well as ongoing technical support to healthcare workers.

 **4,631** professionals trained

5



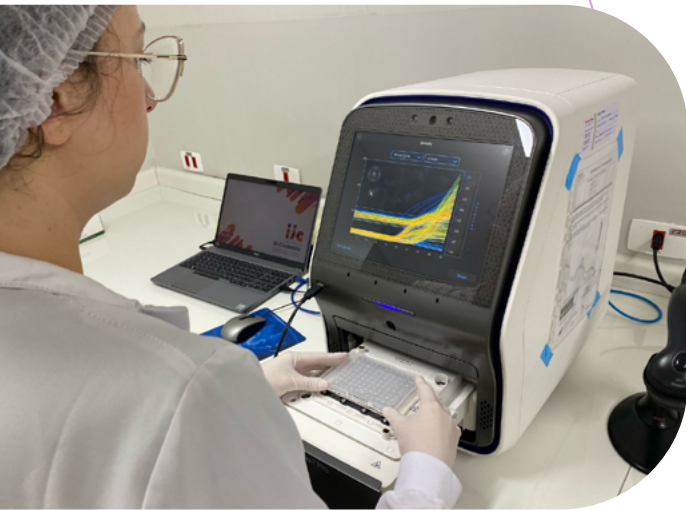
Continuous Improvement

We are committed to advancing the Newborn Screening Test and improving treatment for the diseases it diagnoses. In partnership with pharmaceutical companies such as Novartis, Biogen, and Roche, we conducted a groundbreaking study on Neonatal Screening for Spinal Muscular Atrophy (SMA-5q¹). This study aims to: Map the incidence of the condition, Generate data to inform public policies, Improve referral pathways for patients to reach treatment centers. The study is conducted in collaboration with the Municipal and State Health Departments of São Paulo.

1 | SMA-5q is a genetic disorder that causes progressive loss of movement and may also affect breathing and feeding.

* Family engagement: active involvement of the family in the treatment process
* Training: providing professionals with new skills and knowledge to improve their work
* Incidence: how often something occurs
* Referral: directing someone to the appropriate service or specialist

Real-time PCR equipment used for Molecular Neonatal Screening tests.



Genetic Tests for Neonatal Screening and Research

The technical department of the Instituto Jô Clemente (IJC) Laboratory is not only highly specialized, but also fully equipped to perform all tests related to Neonatal Screening in-house. We use state-of-the-art equipment and advanced methodologies across Biochemistry, Tandem Mass Spectrometry (MS/MS), and Molecular Biology. This space also fosters scientific research and innovation, including projects such as the Pilot Study on Neonatal Screening for Spinal Muscular Atrophy (SMA-5q) in the State of São Paulo.

MOLECULAR BIOLOGY LABORATORY

Opened in 2003, our Molecular Biology Laboratory is equipped with cutting-edge technology and has the capacity to perform the genetic tests included in the Newborn Screening Test: SCID (Severe Combined Immunodeficiency), AGAMA (Agammaglobulinemia), SMA-5q (Spinal Muscular Atrophy).



Types of Neonatal Screening Tests

Basic: Mandatory and free across Brazil; screens for 6 diseases

Super: Screens for 48 diseases using Tandem Mass Spectrometry (MS/MS)

SCID and AGAMA: Detect Inborn Errors of Immunity

SMA-5q: Screens for Spinal Muscular Atrophy, a rare genetic disease

Lysosomal Diseases: Detects 4 rare metabolic disorders

In addition to serving the Unified Health System (SUS) in both the city and state of São Paulo, IJC also offers private testing services for more comprehensive diagnoses* — including SCID, AGAMA, SMA-5q, and Lysosomal Diseases.



313,734

babies screened



2,509,519

tests performed

* Comprehensive: covering a wide and complete range of conditions



III NEONATAL SCREENING CLINIC



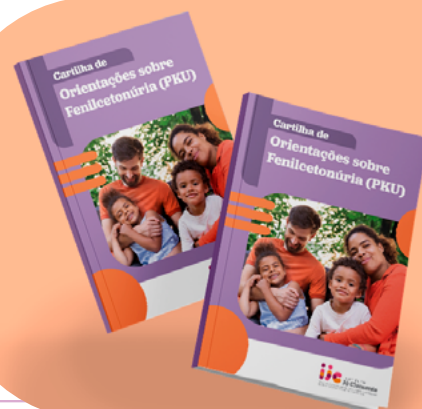
Comprehensive Care for the People We Serve

The Neonatal Screening Clinic at the Instituto Jô Clemente (IJC) provides specialized treatment for three conditions identified through the Newborn Screening Test:

- 1 Phenylketonuria (PKU):** Phenylketonuria is a rare genetic disorder that, if left untreated, can lead to neurological problems, including Intellectual Disability. Treatment consists of a protein-restricted diet and the use of a metabolic formula free of phenylalanine. This amino acid, found in proteins such as meat, eggs, milk, and grains, must be carefully controlled. Ongoing nutritional monitoring is essential to managing the condition effectively.

To provide more information on Phenylketonuria (PKU), we have developed an informational booklet that covers: symptoms, diagnosis, the importance of proper treatment to ensure a high quality of life for those affected by PKU.

 **You can access the booklet [here](#):**



Additionally, we have created a Food Table to guide individuals in managing Phenylketonuria. This table: lists foods that are free, controlled, or prohibited for people with PKU, displays the phenylalanine content of each food item, promoting greater safety and autonomy in food selection, which is crucial for effective management of the condition.



Table with phenylalanine content in foods

Consultation with a nutritionist



*Metabolic formula: a specialized nutritional formula enriched with nutrients but without phenylalanine.

2 Congenital Hypothyroidism: Congenital Hypothyroidism is a condition in which the thyroid gland is unable to produce enough thyroid hormones. This results in a slowed metabolism, which can cause delayed growth, neuropsychomotor developmental delays, and Intellectual Disability.

3 Biotinidase Deficiency: Biotinidase Deficiency is a genetic disorder characterized by a reduction in the enzyme Biotinidase, which is responsible for releasing Biotin from food. Without proper treatment, this can lead to neurological issues, developmental delays, and hearing and vision problems.

Both conditions require regular monitoring and the daily use of specific medications. The care provided is multidisciplinary, involving a team of nutritionists, psychologists, social workers, and specialist doctors.

Without early treatment, these conditions can severely affect a child's neuropsychomotor development and overall quality of life. That's why early diagnosis and immediate treatment in the first days of life are crucial to prevent further complications.

Additionally, periodic development assessments, conducted by our medical and psychological teams, help identify any potential delays in the child's development. This allows for early intervention and referral for targeted therapies. Social Services also plays a key role in supporting families, ensuring access to rights, and promoting adherence to treatment.

6,420
people
served

22,130
consultations
performed

As part of our Early Childhood Prevention and Quality of Life Project, funded by FUMCAD (Municipal Fund for the Rights of Children and Adolescents), we produced awareness videos about these diseases and the importance of early treatment. These videos also provide essential information on: How the service works, The services offered, Guidance on accessing test results. These videos are shown in the waiting rooms of our clinics, helping to educate and inform families.



Psychological Monitoring



Animations shown in the waiting room



III DIVINE DIET



Foods with a Flavor of Inclusion

Divine Diet is a line of special foods designed for the dietary inclusion of individuals with dietary restrictions. These products have low protein content and are gluten-free, nut-free, milk-free, egg-free, and animal derivative-free. They are ideal for individuals with conditions such as Phenylketonuria (a rare disease diagnosed through the Newborn Screening Test), lactose or gluten intolerance, cow's milk protein allergy, peanut and nut allergies, as well as those who follow a vegan or vegetarian diet.

The production process adheres to strict quality control standards to prevent contamination, ensuring both food safety and delicious, accessible products. The Divine Diet portfolio includes around 50 items, with special seasonal options for holidays like Easter and Christmas.



Alana, a young woman benefiting from the Special Basket project at the Divine Diet store.

Conheça mais:



Escarole Pie.

Solidarity at the Table for People with Phenylketonuria

People with Phenylketonuria who are in social vulnerability, and are supported by the Instituto Jô Clemente (IJC), receive a monthly voucher to select specific foods for their diets from the Divine Diet Store. The food is tailored to their preferences and needs. This initiative is made possible by donors, both individuals and organizations, who sponsor the beneficiaries of the Special Basket. One such sponsor is the IHF - Instituto Helena Florisbal, which has supported this initiative since 2023.

You and/or your company can contribute to the cause by sponsoring a child



Increasing Visibility for Restrictive Diets

We participated in NaturalTech, the largest event in the natural products sector in Latin America, aiming to increase the visibility of Divine Diet products and to create new business opportunities.



Equipe do IJC na feira Naturaltech.

6,167 Kg
of food produced

1,352 baskets delivered
marking a **9.8%** growth compared to the previous year

*Beneficiaries: Individuals who receive benefits or are supported by a given initiative.