



## 1. President

Instituto Pequenos Grandes Guerreiros was formally founded in 2016. It was a year of beginnings, ideas, the joining of forces, the building of a team and the reunion of talents. Our project plan was defined and important partnerships came together, especially in the medical sector. The psychological assistance program started. The creation of our Facebook page and Instagram profile meant that parents of babies affected by NEC in Brazil could find a channel where they would be able to read about other children affected, get a better understanding of the disease and seek psychological assistance while providing Instituto PGG with a better view of the NEC landscape in Brazil and what can be done in terms of fostering prevention and treatment best practices. We are consolidating our activities in 2017, while expanding our partnerships, with the aim of becoming a reference to families of affected babies.

Thank you,

Simone Ramalho Rosito  
President of Instituto Pequenos Grandes Guerreiros

## 2. History and Objectives

Instituto PGG was formally founded on the 9<sup>th</sup> March 2016, inspired by Antonio Rosito Robyn, a premature twin born at 32 weeks, 1150g weight, who was doing well and apparently heading towards discharged when, at 3 weeks old, he developed surgical necrotizing enterocolitis. Tom ended up losing most of his intestines as a result, acquiring short bowel syndrome and passing away at the age of 10 months and 11 days.

Surprised and not conforming with the lack of information and knowledge about a disease which affects 10% of preemies worldwide, with 10% of babies affected by it having been born at full-term, his family and their friends mobilized efforts towards the creation of an institution which would not only provide information about NEC but also psychological assistance to families of affected babies.

Instituto PGG offers psychological assistance to parents, siblings, grandparents or any other family member in need of support. The aim is to better equip family members to deal with the challenges brought by the disease.

Instituto PGG offers information about NEC in a way that people not familiar with medical sciences will be to understand it, thus feeling better equipped to talk and ask questions to doctors and specialists.

Instituto PGG wants to shed light on NEC incidence in Brazil and to do so it is currently conducting a data collection project to map out its occurrence in Brazil.

### 3. Our Team 2016/2017

CEO: Simone Ramalho Rosito

Director: Mariano Ardisson

Advisory Board:

Eric Fonseca (Chairman)

Bia Rosito

Adriana Telles

Isabella Fiorentino (Ambassador)

Rodolfo 'Rudi' Fischer

Luciana Gallo de Mesquita

Renato Consoni

Vera de Oliveira

Natalia Kerkis (Fiscal Board)

Romualdo Tiseo (Fiscal Board)

Chief Medical Advisor

Dr Celso Rebello

Volunteers

Renata Condes – Technical advisor

Maria Luiza Ramalho Rosito – Technical advisor

Eloisa Simionato

Patrícia Kriger

Hortênsia Rosito

Agatha Machado Alves

Ana Paula Lopes dos Santos

Geisa Gomes

Demétrius Soares

Ivan Martinho

Dr André Laranjeira (neonatologist)

International Advisors

Jennifer Canvasser

Dr. Rodrigo Vianna

The whole PGG team currently works on a volunteering basis, with no paid employees.

### 4. Infrastructure

Instituto PGG does not currently have physical headquarters. Our current operations do not require it at the moment, especially considering the careful use of resources and the aim of keeping expenses under tight control. This way, our meetings are usually held in rooms made available by our supports and the psychological sessions are held either at our volunteers' own therapy rooms or are spaces rented out per hour for the purpose, as shown in our income statement. Therapy sessions occur throughout the City of Sao Paulo, as per the convenience of our beneficiaries and availability of our volunteers.

## 5. Objectives

### 5.1 Psychological assistance

The arrival of a baby represents a major change in the lives of parents. The presence of a sick baby represents more than just a change but also a challenge. Dealing with reality versus expectation is difficult enough but a long term hospital stay may have some actual [practical] consequences on the lives of family members. It is not unusual for one of the parents to have to give up employment to accompany the baby, which may in turn increase financial pressure. This new reality brings social changes, given how relationships and availability to friends are drastically altered. Siblings of babies affected by NEC experience a decrease in their parents' availability, which creates another delicate situation for parents to deal with. Psychological assistance aims at orienting these parents to deal better with the challenges brought by having a sick baby.

Instituto PGG has seven volunteer psychologists, trained to understand the disease and its treatments, the NICU environment and the particularities of having a sick baby. Our volunteers meet once a month to discuss cases and theory and they actively participate on the organization's strategic planning.

Since its formal establishment in March 2016 until the end of 2016, Instituto PGG provided psychological assistance to seven people, all finding us via Facebook. In March 2017, Instituto PGG announced a partnership with Santa Casa de Misericórdia de São Paulo, establishing that the hospital recommends PGG's services to families of babies affected by NEC after discharge or death. Instituto PGG is working on setting up similar agreements with other institutions.

Instituto PGG got granted permission by the Federal Board of Psychologists to offer remote assistance via electronic means. This way, PGG is able to service families of babies in any place in Brazil. This is in line with the Health Ministry's policy of using Telemedicine to ensure universal health and it is particularly important to families located in remote areas where there is a scarce presence of trained psychologists.

Over 50 family members, predominantly mothers, have contacted us throughout our first year of existence to share their experiences. In May 2017, Instituto PGG experimentally held the first group meeting of families affected by NEC, in São Paulo, with the presence of 12 family members and three psychologists.

### 5.2 Data collection on NEC incidence

One of the main problems in dealing with NEC is the lack of visibility. This is actually a global phenomenon but it is particularly accentuated in Brazil. The number of cases reported and the mortality rate are very vague. The best source for data is Fiocruz's Rede de Pesquisa Neonatal. However, the cases reported by this network include only infants born weighing less than 1500 g, limited to participating reference institutions.

Instituto PGG developed a questionnaire which while being very detailed it is also easy and fast to be filled in, contemplating a variety of relevant questions with regards to premature birth and NEC incidence. The aim is to build a database of NEC incidence in Brazil. The aggregated results will be released annually and the database will be available to research.

The pilot project started in July 2017, with 5 institutions, a number which has since increased to 10, with the aim at testing the questionnaire and its availability. The pilot phase is expected to last 6 months. At the end of the pilot phase, with the questionnaire well tested and approved by users, PGG will expand its distribution so that at least 70% of Brazilian NICUs will be among the respondents, with the geographic representation of every single Brazilian state.

### 5.3 Awareness

Instituto PGG raises awareness on NEC. In Brazil, as well as abroad, families tend to find out about NEC's existence only when they are touched by it. We work constantly and tirelessly to change this scenario, so that NEC becomes widely known. We raise awareness predominantly via social media, especially Facebook and Instagram. Instituto PGG also tries to draw the attention of the press to the disease. Mother of premature triplets, TV presenter Isabella Fiorentino is Instituto PGG's ambassador and Board member.

The 'geladeirotecas' (broken refrigerators with books inside them, like a library) 'Viva o Tom', located in Parque Buenos Aires, a public area in central Sao Paulo, also serve as a way to raise awareness about NEC as well as publicise Instituto PGG's activities. Books, donated by friends or the public, are stamped and have a leaflet explaining NEC attached to them. Users can take them home and return them at a later date or simply replace them with another book.

## 6. Human Resources

In its first year of existence Instituto PGG's collaborators were all volunteers.

## 7. Financial Summary

Instituto PGG is a non-governmental, not for profit organization, managed with value-creation first and foremost in mind. Its first year of existence was a year learning and because of that it was agreed PGG would not ask for public donations in this period. All revenues came from donations from collaborators. The main source of revenues were sales of the book 'Ai meu Buda! Relatos curiosos de viagens singulares'. The book is not sold by PGG itself but by its author, Simone Rosito, who then donates all the financial proceeds to PGG.

On its first year of existence PGG was extremely conservative with expenses. With its the operations still small, PGG could afford to use pro-bono services most of the time. This way, its main cash outflows were bank fees, expenses for PGG's formal establishment and

reimbursement for the rent of room for psychological sessions. While the Brazilian law requires for volunteering work to be accounted, it is important to highlight that it doesn't mean a cash flow but simply the monetary representation of the value of volunteering work. This was worked by multiplying the official rate as per the CRP (the regional psychology council) by the number of hours worked.

## 8. Income Revenue and Balance

<b>R\$ Income Statement 2016</b>	
Revenues	11.204,95
Donations	11.204,95
Volunteers	6.578,00
Volunteering work	6.578,00
Commercial expenses	7.723,00
Professional services	6.778,00
Rent	945,00
Taxes	243,44
Taxes	243,44
Financial expenses	222,51
Interest and fines	21,51
Banking charges	201,00
Financial revenues	0,28
Interest	0,28
<b>Surplus</b>	<b>9.594,28</b>

<b>R\$ - Balanço Patrimonial 2016</b>			
<b>ATIVO</b>	<b>10.539,28</b>	<b>PASSIVO</b>	<b>10.539,28</b>
Ativo circulante	10.539,28	Passivo circulante	945,00
Disponível	10.539,28	Exigível a curto prazo	945,00
Caixa	250,00	Outras obrigações	945,00
Caixa geral	250,00	Outras contas a pagar	945,00
Banco conta movimento	10,00	Patrimônio líquido	9.594,28
Itau	10,00	Patrimônio líquido	9.594,28
Aplicações financeiras	10.279,28	Reservas	9.594,28
Itau	10.279,28	Superavit/deficit do exercício	9.594,28

## 9. 2017

- Partnership established with US-based organization NEC Society for the exchange of information on the disease and increasing efforts for raising awareness.
- Membership in the Preemie-Parent Alliance – PPA – which encompasses 38 organizations which work to provide support to parents of premature babies. PGG is the first international organization to be part of PPA.

- Start of the pilot phase of mapping out NEC incidence in Brazil.
- CRP authorization for remote psychological assistance.

## Conclusion

The establishment of partnerships with hospitals, especially those part of the pilot phase of the mapping out project, and the authorize for online psychological assistance, are expected to represent an increase in the number of family members of affected babies assisted.

During the pilot phase of the mapping out project PGG will introduce it to other institutions in order to build momentum when the time for national expansion comes. A video will be made expanding how the questionnaire works and a manual will be produced to alert health professionals, especially those in remote areas, about the disease.

International partnerships will be consolidated. PGG counts with the support of Dr Rodrigo Vianna, director of Miami Transplant Institute, and Jennifer Canvasser, founder and president of the NEC Society, who is PGG's international advisor. PGG is also in contact with SIGNEC, a British Interest Group on NEC. The three organizations want to take a global stance fighting the disease and hopefully liaising with similar organizations in other parts of the world to further awareness, prevention and foster research.

While the small size of PGG's operations in this first year of experience enabled it to use pro-bono work and to solely rely on volunteers, its growth will demand more service efficiency, thus increasing expenses are expected. In 2018 it will be inevitable the hiring of employees.

With the public release of PGG's first year results and clear objectives for the future Instituto PGG plans to start receiving public donations in 2017. Using the same transparency rationale, PGG will go after partnerships with companies. With the publishing of its financials, PGG will protocol the request for the certificate of public utility with the City of Sao Paulo.

Sao Paulo, 28 July 2017