







## **Paulo Gontijo**

projects, I am always working more and more, and will keep doing so as long as I live." Paulo Gontijo



#### IPG Objectives









IPG has been working all these years with the main objective of promoting knowledge about ALS. For this reason PG Award was created, as an incentive to research on ALS and also *Todos Por ELA (All for ALS)*, a Brazilian interactive site, managed by professionals, whose objective is organize and convey information to the **ALS** community.







Will be awarded on 30 November at the

#### **PG Award 2011 MND Association**

From 2010 on, **PG Award** counts on the support of **MND Association** for the promotion and delivery of the prize.

The next **PG Award** will be delivered on December 2011 at **The ALS International Symposium** in Sydney Australia and is intended for young researchers.

The best research will be rewarded with **U\$ 20,000** (twenty thousand dollars).

Support



IPG
Instituto Paulo Gontijo
ipg.org.br



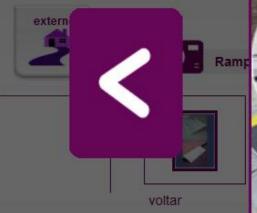
mnda motor neurone disease association

> mndassociation.org UK

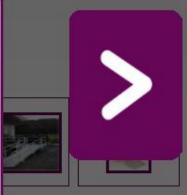


Introdução ▼ Dificuldades \* Meu Corpo ▼ Acessibilidade ▼

MANUAL INTERATIVO | ESCLEROSE LATERAL BRASILEIRO DE | AMIOTRÓFICA







#### Rampa portátil

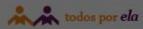
Rampa portátil para pequenos desníveis.

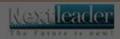
Frabricante: Homecraft

Modelo: Advantage Series Suitcase Ramps





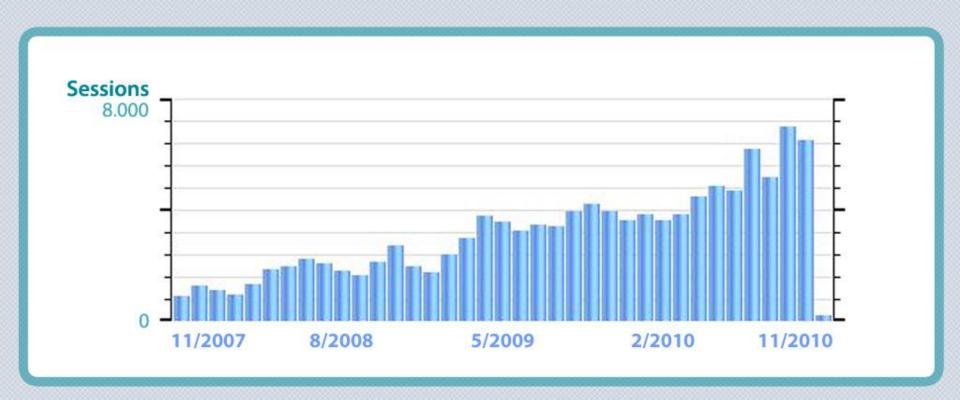




## Report



#### **Graph Sessions - IPG**



Total Range: 115.944

Monthly Average: 3.133,62

## **IPG New Projects**



#### **Projects 2011**

For 2011 IPG intends to engage in actions which may make the community aware on how necessary it is to provide high quality care for ALS patients. We fully understand the importance of conveying sound information for the entire Brazilian territory, since currently only the more developed regions receive accurate information. This can be achieved not only through regional symposia but also through a work dedicated to better qualify the professionals. In order to do this, besides using our own budget, we will take actions for fund raising so that our capacity to achieve our goals may be expanded.



Silvia and Dee Norris

#### "Todos Por ELA" Team





Francisco Rotta Neurologist



Sheila Tortorella Translator

We would like to thank everyone who joined us in this project and work for the last 5 years.



Adriana Klein
Occupational Therapist



Patrícia TTeixeira
Trixe - Press Office



Silvia Tortorella

Executive Director



Miguel Mitne Neto
Biologist



Betho Lima
Cooperator



Marcela Gontijo

Vice President



Silvia Nakazune

IPG Office



Adriano Brandão

Art Director



Paulo Gontijo
President

#### Thank you

We would like to conclude this presentation highlighting our immense satisfaction in becoming members of this Alliance.
See you in 2011 in Sydney.



## www.alsmndalliance.org

International Alliance of ALS/MND Associations



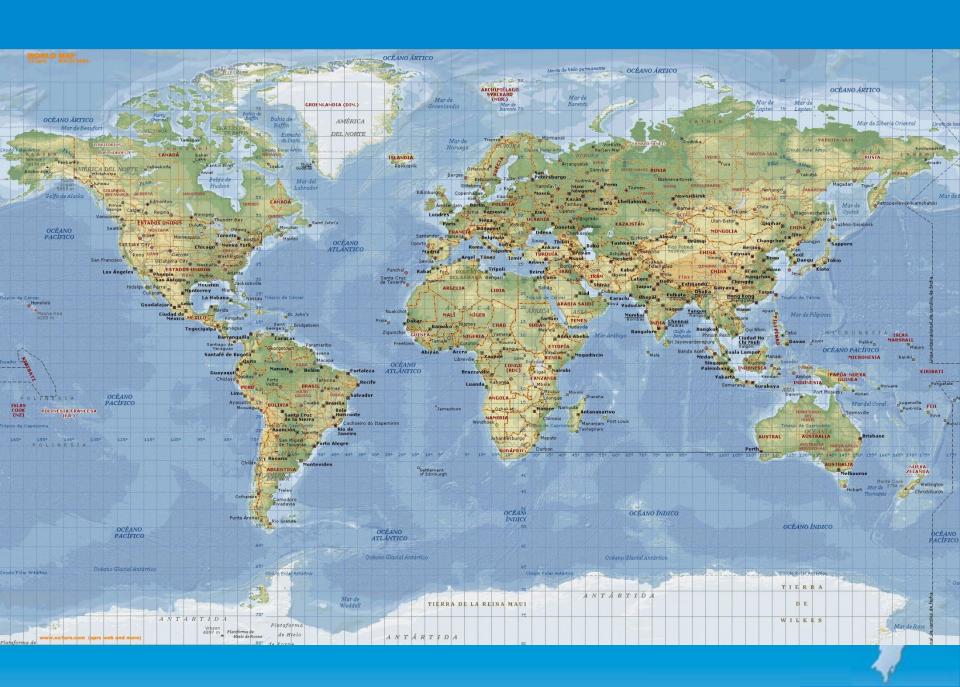
www.ipg.org.br

## **ABrELA**

# Tatiana Mesquita e Silva President Associação Brasileira de Esclerose Lateral Amiotrófica - ABrELA

Orlando - Dec.2010







Area: **8.514.876,599** km<sup>2</sup>

(47% of South America)

N-S: 4320 km

E-W: 4328 km

3 time zones

Population: 192 mi





## ABRELA

 Founded in 28/06/99, in São Paulo, by a group of neurologists involved in ALS care

 Located at the Neuromuscular Disorders Clinic – São Paulo State Federal University School of Medicine

1291 patients on file in 2006



## ABRELA - Personnel

Two social workers

 Medical and rehabilitation professionals through cooperation program with the

University

Volunteers







Ceramicist - volunteer

1st. Meeting in 2001 for Patients, careguivers and health Professionals.



1st. ALS Symposium in 2002



## ABRELA - Mission

➤ To promote better quality of life to ALS patients through information, education and social support to both patients and families, as well as to inform the general public and professionals with interest in this disease and its treatment.



## **ABRELA: Patient-oriented actions**

Local: Neurological, rehabilitation and social services.

General: Patient registration

Information packages

Specialist referrall

Provision of equipment

Legal advice

Web-based information:

www.tudosobreela.com.br

## Political actions

 Protocol to dispense Riluzol as a high-cost drug – July of 2002

 State-provided non-invasive ventilation (BiPap) – São Paulo in 2003



Sponsored meetings

 National ALS Symposium (5th in 2006) – Patients and caregivers wellcome

Spring Festival Opportunity for patients
 and experts to socialize
 and exchange information



# VII Brazilian symposium







# VIII Symposium







2nd IPG Award and the first year it was International.



## **ABrELA**



#### 2008

- 1.291 patients;
  - 1,7% North
  - 6% Northeast
  - 4,2% Central-West
  - 72,3% Southeast
  - 15,4% South



## Regional Branches



Affiliated with ABRELA

Know-how transfer

 2006 in Rio Grande do Sul and Minas Gerais

 2009 in Rio Grande do Norte

# Thank you







