

ALS Pro-Cure Association



6 years of a successful story

Attention to people with ALS through social networks:

This is possible!

6 years of a successful story!

Alessandra C. Dorça



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

The impact of social networking on society

▶ Cultural

- New habits

▶ Business

- Loyalty and interactions

▶ Policies

▶ Health

- Access to knowledge;
- Possibility of learning;
- Need for relationships.



Social network impact on ALS

- ▶ **Knowledge for all**
 - Access to new medicines;
 - Access to new world studies and work.
- ▶ **Opportunities for treatments in other countries**



Social network impact on ALS

► Relationship

- Understand the other's condition;
- Provide answers to the same questions;
- Realize that you are not alone;
- Feel in a new family.



The surprise!!!!

- ▶ In 2014, with the **Ice Bucket Challenge**, the ALS Pro-Cure Association became known all over Brazil;
- ▶ The association raised more than \$ 250,000 with the campaign;
- ▶ The number of participants in the group increased by 400%;
- ▶ Brazil's largest ALS patient care group was born.



The biggest challenge

- ▶ Provide care, support, guidance and equipment to the patients all over the country;



AMBU

Cough assist machine



Non-Invasive Ventilation Fans

TOBII Eye



Food

The biggest challenge

- ▶ Enable **caregivers** and **health professionals** in the knowledge and treatment of the disease.



2018 Study

- ▶ **In 2018 we conducted a small study with our group.**

We asked each healthcare professional to record the number of appointments online for 1 month

- ▶ **Participating Professionals:**

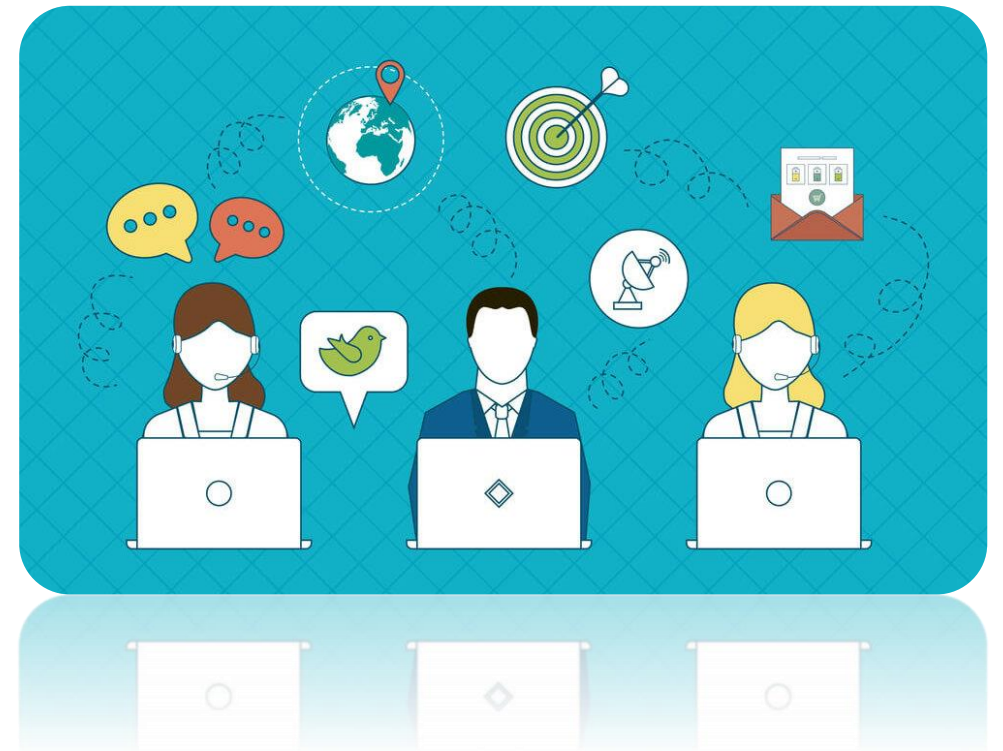
- 6 Physical Therapists (4 respiratory and 2 motor);
- 2 Speech Therapists;
- 2 Nutritionists;
- 2 Psychologists.



2018 Study

► The following services were considered:

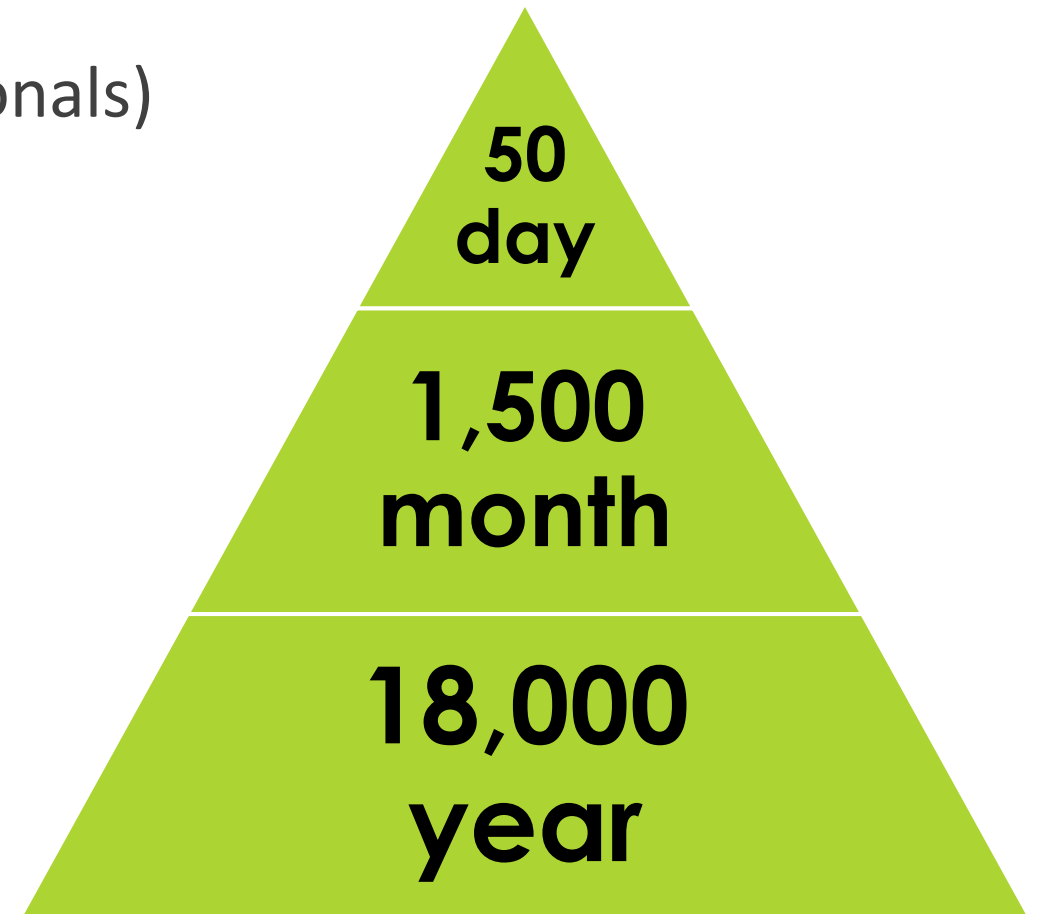
- Responses to Facebook posts;
- Video calls;
- WhatsApp calls;
- Service “in loco”;
- Support Team Training.



Results of 2018 study

- ▶ **50 visits / day** (divided among professionals)
- ▶ **1,500 visits / month**
- ▶ **18,000 visits / year**

Note: The services are divided among the various professionals of Pro-Cure



Results of 2018 study

► Most common service and guidance:

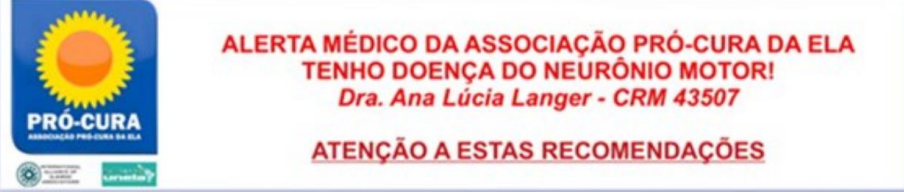
- How to perform breathing exercises;
- Nutritional Guidelines;
- Use of Non-Invasive and Invasive Ventilation Fans (best equipment and ideal strategies);
- Swallowing issues;
- Psychological issues (internal conflicts, family conflicts, etc);
- Many other issues about daily life;
- Bath, teeth cleaning, bed positioning, wheelchair type.

Our network information materials

- ▶ YouTube Channel – 8,500 Subscribers (**one of the largest in the world**)
650,000 views;
- ▶ Instagram – more than 20,000 followers;
- ▶ Videos about breathing exercises with AMBU;
- ▶ Clarification Lives on Mechanical Ventilation Issues, Mask Types, Tracheostomies;
- ▶ Nutrition Guidance Lives;
- ▶ Association Lessons & Events.

Our network information materials

- ▶ Medical Alert (*photo*);
- ▶ Home Care Request Petition Templates;
- ▶ Primer *Did You Know?*
- ▶ Practical guidelines with accessible language for caregivers, patients and professionals.



**ALERTA MÉDICO DA ASSOCIAÇÃO PRÓ-CURA DA ELA
TENHO DOENÇA DO NEURÔNIO MOTOR!
Dra. Ana Lúcia Langer - CRM 43507**

ATENÇÃO A ESTAS RECOMENDAÇÕES

1. Na falência ventilatória não aplicar oxigênio por cateter ou máscara. Somente se acoplado à ventilação.
2. Drogas contraindicadas: halotano e succinilcolina.
3. **Contraindicados os opiáceos** (tramal, morfina, codeína, etc) e os **benzodiazepínicos**. (frontal, lexotan, rivotril, etc)
4. Usar com cautela os relaxantes musculares.
5. Cuidado com drogas psicoativas: **risco de síndrome neuroléptica maligna**.
6. Nos episódios secretivos iniciar rapidamente o uso de antibióticos.
7. Introduzir manobras de auxílio à tosse nos episódios em que o paciente se apresente secretivo e com tosse pouco potente. Utilize das manobras de tosse manualmente assistida (ambu – ressuscitador manual) ou, quando possível, tosse mecanicamente assistida (assistente de tosse - cough assist)
8. Em casos de quedas com fraturas de ossos longos se houver deterioração neurológica ou sintomas como falta de ar, considerar a possibilidade de embolia pulmonar.

Our current numbers

- ▶ Facebook group
more than 23,000 members



A Associação
Promovendo informação e o auxílio a **pacientes de ELA**, seus **familiares** e **cuidadores**.

 procuradaela.org.br

 contato@procuradaela.org.br

 (11) 2659-7912

 (11) 94208-0123

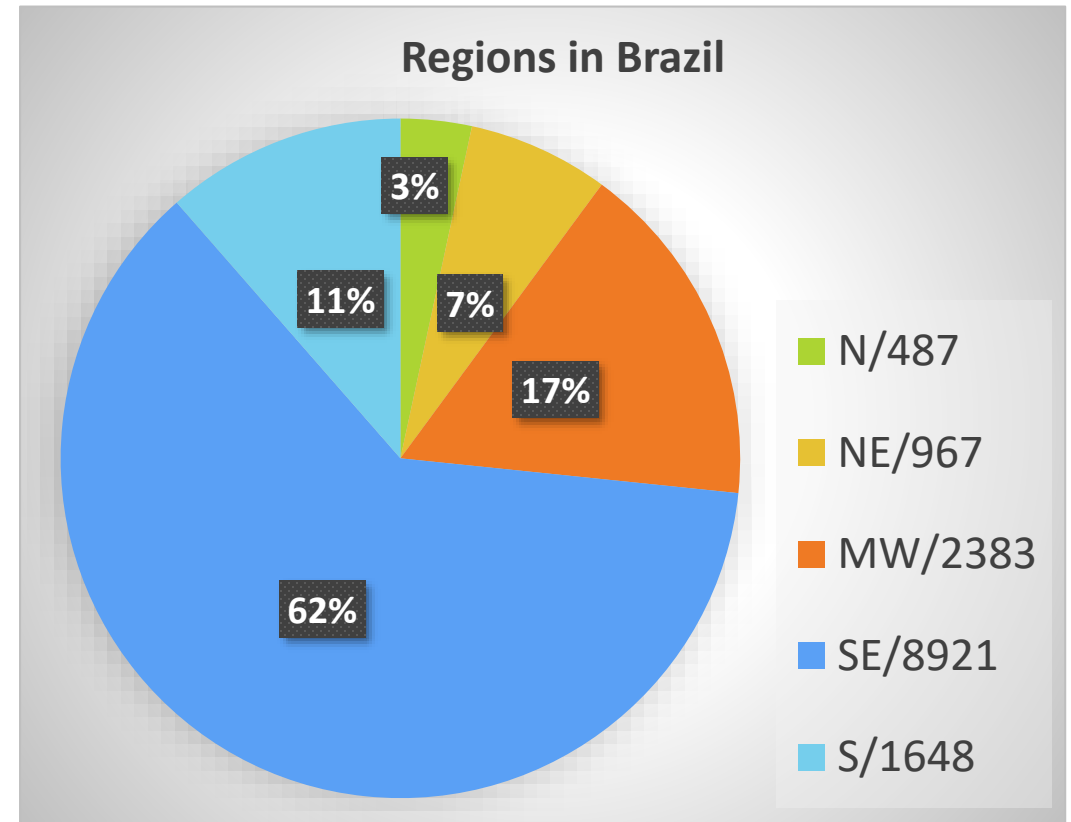
 **Editar**

Grupo de Associação Pró-Cura da ELA

Pró-Cura da ELA >
GRUPO PRIVADO 23,5 MIL MEMBROS

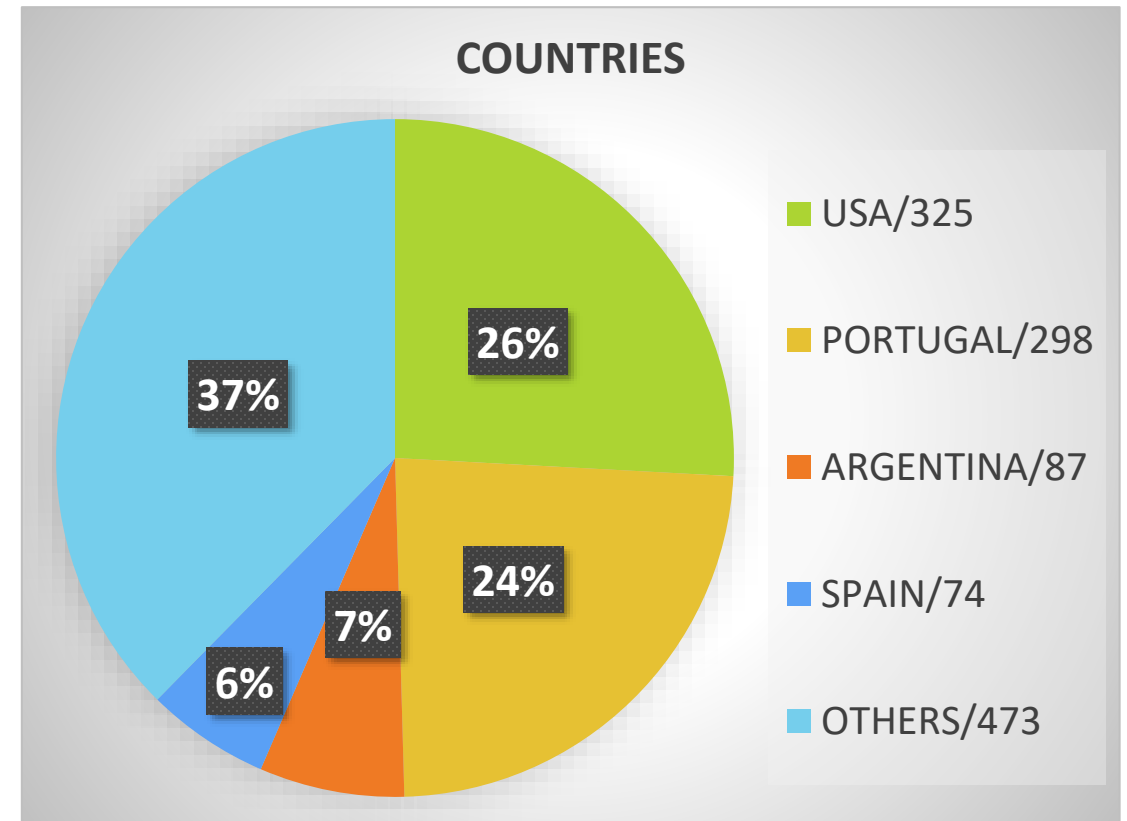
Interactions by regions in Brazil

- ▶ Largest number in the southeast:
 - Larger population;
 - Higher per capita income and assistance.



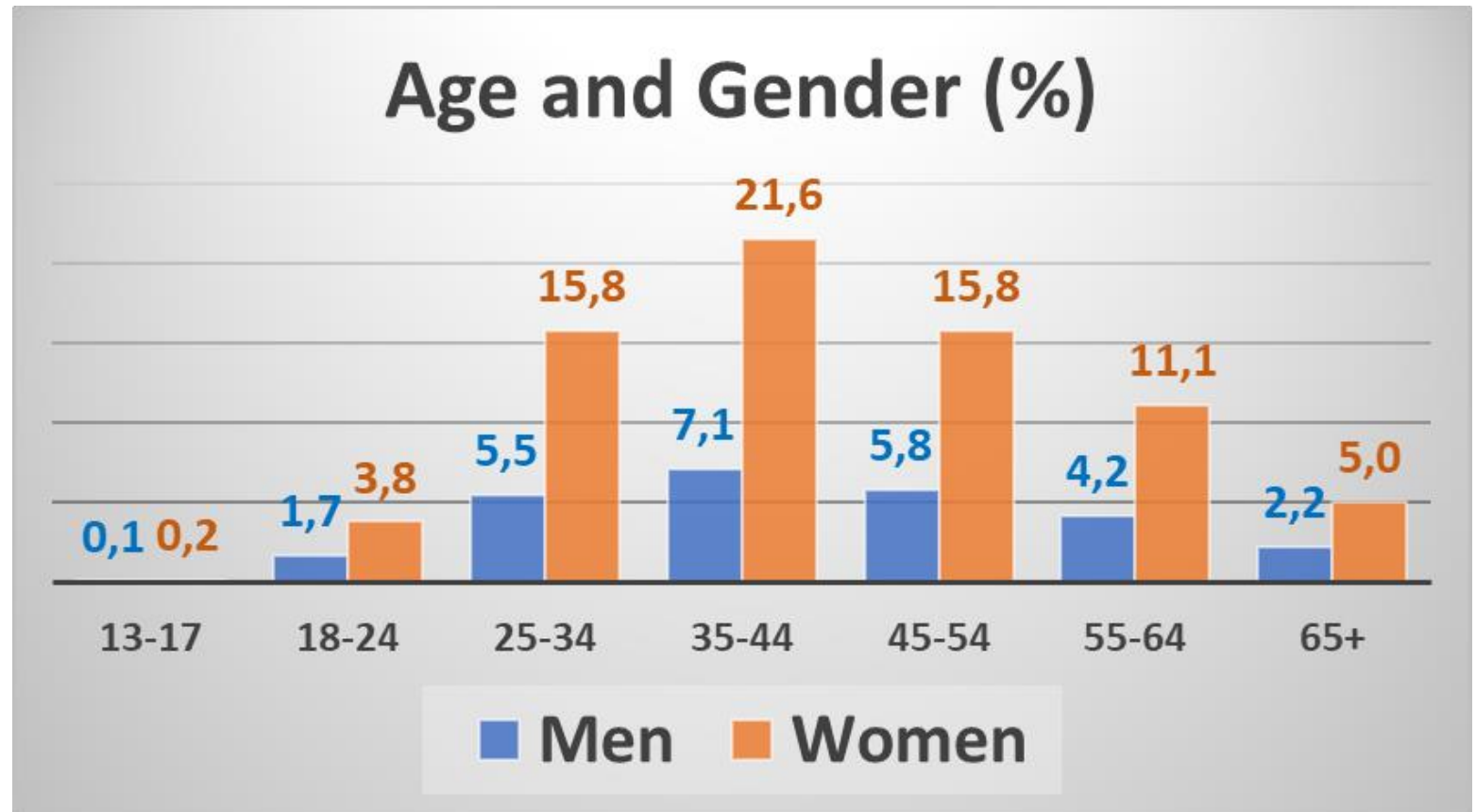
Interactions in the world

- ▶ Great attendance in the USA and Portugal;
- ▶ Followers all over the world.



Age and gender

- Most hits by women
- Age range 35-54 years



Enilton video 1



Enilton video 2

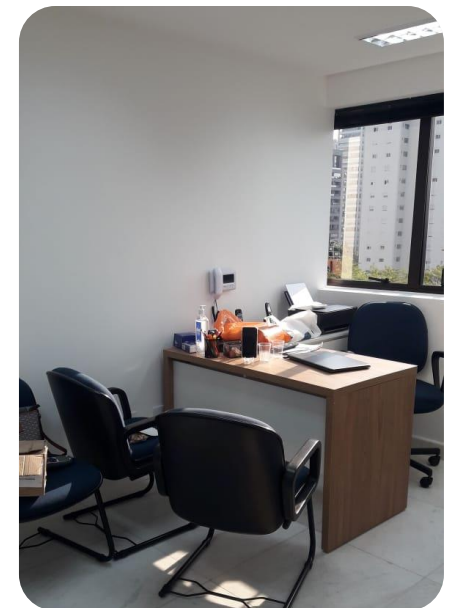


New headquarters 2019

Consulting Room



Supply Room



Social Worker Room

Who we are

□ Executive Directors:

- ▶ *President:* Jorge C. Abdalla Jr.
- ▶ *Vice President:* Andreza Diaféria
- ▶ *Administrative Director:* Sylvania J. Almeida
- ▶ *Financial Director:* Christina S. Abdalla
- ▶ *Technical Director:* Alessandra C. Dorça



Who we are

□ Deliberative Council:

- Rogério Salgado Gomes – President
- Clarice Viviane Karkow
- Fábio Carvalho
- Maria de Fátima Gasparini
- Simone Gonçalves de Andrade Holsapfel
- Tamara Elisa Rocha Braga
- Thiago Mendes Tavares
- Vanderlei Corradini Simões de Lima
- Vania de Castro Moreira



Who we are

❑ Fiscal Council:

- Alessandra Aparecida Gasparini
- Marcelo Farinelli
- Paulo Sérgio C. Dorça

❑ **Scientific Committee;**

❑ **Steering Committee;**

❑ **Social workers;**

❑ **Collaborators and volunteers.**



TOGETHER WE ARE STRONGER



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS



FEBRARARAS
FEDERAÇÃO BRASILEIRA DAS ASSOCIAÇÕES DE DOENÇAS RARAS

Thank you!!!

