ALS Pro-Cure Association
Attention to people with ALS through social networks: This is possible!

6 years of a successful story!

Alessandra C. Dorça
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.
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

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

Home Care Request Petition Templates;

Primer *Did You Know?*

Practical guidelines with accessible language for caregivers, patients and professionals.
Our current numbers

- Facebook group
  more than 23,000 members
Largest number in the southeast:
- Larger population;
- Higher per capita income and assistance.
Great attendance in the USA and Portugal;

Followers all over the world.
Age and gender

- Most hits by women
- Age range 35-54 years
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: Silvania 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.
Thank you!!!