HOW ARSLA SUPPORTED CAREGIVERS

Christine TABUENCA - 01 december 2019
8 000 personnes vivent avec la maladie en France.

10 à 20% des cas sont des formes familiales donc génétiques et héréditaires.

La maladie touche 1,5 hommes pour 1 femme.

55 ans Âge moyen en début de maladie.

3 nouveaux diagnostics par jour, ce qui en fait la maladie rare la moins rare.

150 000 personnes dans le monde vivent avec la maladie.

1 200 décès par an.
WHO IS ARSLA ? 35 YEARS OF WORKING

Non-profit organization borned in 1985
of the association of one patient and his neurologist
to better understand this disease

2 main tasks

To assist and improve patients for a better quality of life
Support for research to cure the disease

The biggest french non profit organization in ALS

Non-profit organization funded by
public generosity at 98 %
KEY NUMBERS OF THE ARSLA

- 900 000 € for research grants
- 70 000 € for young researcher
- 750 000 € for MINE
- 2 young research Award

- 3 000 people benefited from a material loan
- 980 caregivers benefited discussion group
- 1 000 supported by social worker
- 2 300 calls received to the hotline
IN 2017, A NATIONAL STUDY TO KNOW THE NEEDS OF CAREGIVERS
WHO ANSWERED?

- 1 000 FAMILY CAREGIVERS
- 200 BEVEREAD CAREGIVERS
- 600 PROFESSIONNAL CAREGIVERS
1. How caregivers know us?

- From ALS center: 70%
- From Internet: 10%
- From another patient: 20%
THE RESULTS FROM FAMILY CAREGIVERS

- To find solution to take care better their patient (42%)
- To find listening and talk with other caregivers (31%)
- More information about the cure (23%)
- To have respite (4%)
THE RESULTS FROM PROFESSIONNAL CAREGIVERS

- Learning specificity of ALS
- To be formed
We decided:

⇒ To reinforce existing actions
⇒ To create new action
** We want to value the work of caregivers who find simple and effective solutions to help the patient to eat (for example when you mix broccoli, it becomes bitter, a caregiver finds a solution by putting sugar and curcumin.

** We launched 2 recipe competitions: one traditional recipe and another for celebration (Christmas, easter...).
Cooking workshop every two months!

Animated by a caregiver and a chef cooking in a famous place in Paris: Ecole FERRANDI

10 participants

2 goals:

=> To learn how to cook chopped and mixed recipe
=> To give the possibility to exchange between caregiver
=> To take pleasure

In 2020, we’ll develop cooking workshop in 2 places outside Paris
Accompagner la vie, vaincre la Maladie de Charcot
3. A SPECIFIQ HOTLINE

- Run since 10 years only with volunteers who have been concerned by ALS – Most of them are bereaved

- Today, it’s 50 % volunteers and 50 % professionnal (social worker, physiothérapist, psychologue)…. Because the needs of caregiver are now more technical

- Since 2 years, we training this volunteers how to listen , how use their own experience to be more empathic, how to work together with social worker. For example, il a person talk about technical question like research, the volunteers gives the call to one of the professional employees of the association or a doctor

- 2 annual training for all volunteers animated by a psychologue, a neurogist and me

- We wroted a specific guide with the most frequently questions to help the volunteers.

In 2019, 2 000 calls were received at this time.
REASONS FOR APPEALS

- Listening: 23%
- Help for administratif process: 14%
- Information about ALS, cure: 17%
- Medical equipment: 21%
- Information about research, clinical trials: 25%
4. A BOOK/ GUIDE

We have written a guide about what they have to do at each stage of the disease: since diagnosis to after the death because the caregiver stay alone without support.

There is 2 versions: one light without reference of death and one more completed.

The neurologist give the light version to the caregiver when he announced the diagnosis. When the caregiver will contact the organization, the other version will be give him.

In 2019, 6 500 guides have been distributed in ALS Center.
5. SPEAKING GROUP OR THERAPY GROUP

- Only for caregivers (volunteers or professionnals aren’t admissible)
- Each month
- to exchange outside traditional places of care
- Closed place that protects speech
- to exchange emotion, feeling without judgment
- with a psychologue who isn’t engaged on the cure
- It’s an open group: caregiver come when he need or when he can (sometimes is difficult to find somebody to stay with the patient)
5. SPEAKING GROUP OR THERAPY GROUP

- 10 participants maximum
- The psychologists have a big experience on neurodegenerative disease
- In 2020, we’ll create four new groups
WE NEED YOU FOR THE NEXT STAGE

- We launch a new recipe competition, an international competition
- for all caregivers
- For international chef
- All information on the website in English and Spanish
STEP OF COMPETITION

**Step 1 - The contest**
Anyone can offer one (or more) recipe(s) with a picture of the meal, which will be posted on our dedicated Facebook page Novembre 2019 from January 2020.

**Step 2 - Public vote**
On February, the internautes choose the 30 most recipes which are submitted to the final jury, which will take place on April.

**Step 3 - Jury final**
This committee will consist of:
- Patients, because they are the first concerned
- Caregivers,
- Professional Health (occupational therapist, nutritionist...)
- Our official sponsors

**Step 4 - Announcements of results and valuation of recipes**
Award will take place on June 21, the day of the World ALS Day – The price: 2 days in Paris all inclusive for two persons.
Merci