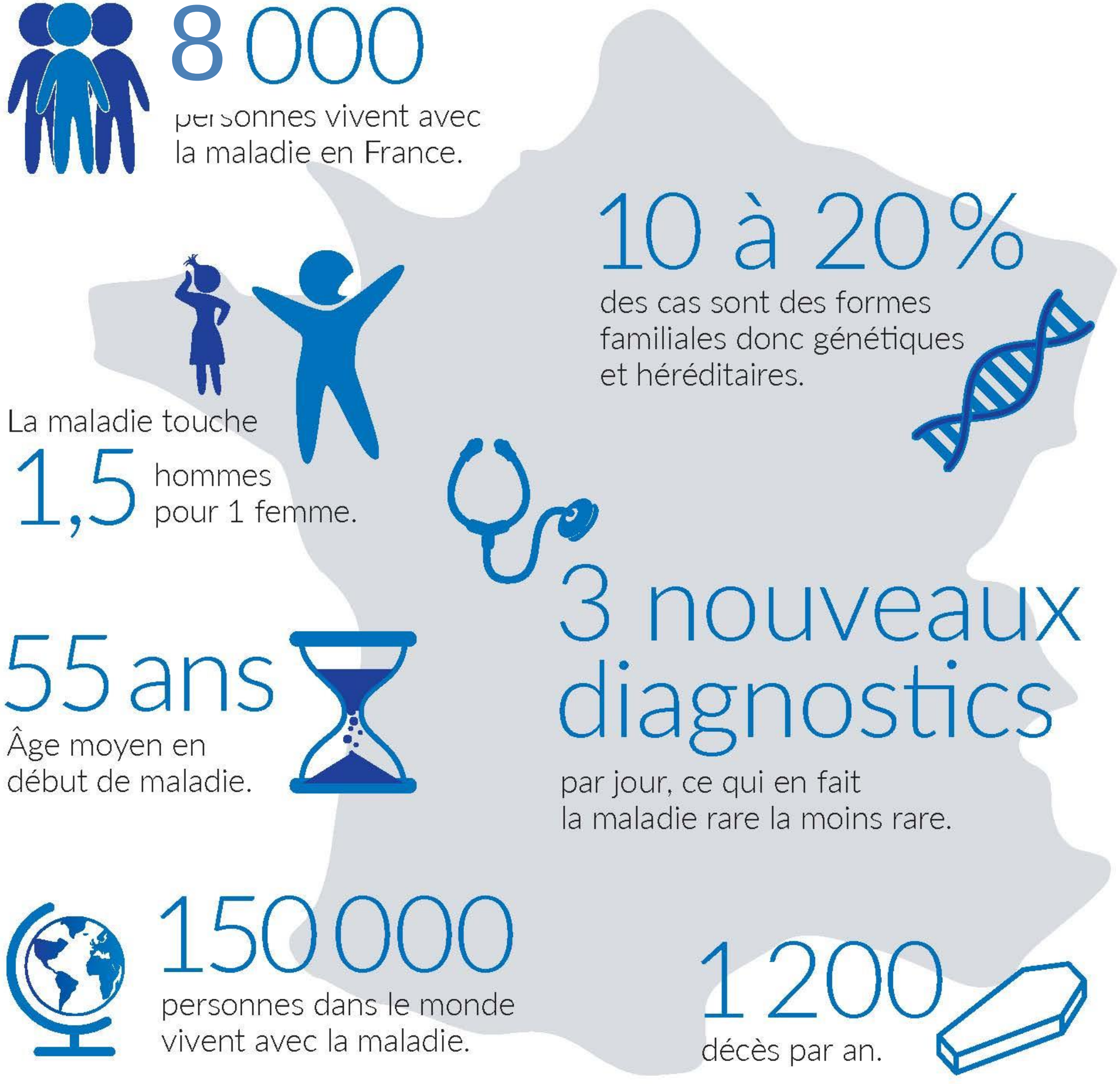
HOW ARSLA SUPPORTED CAREGIVERS

Christine TABUENCA - 01 december 2019

Accompagner la vie, vaincre la Maladie de Charcot

FRENCH EPIDEMIOLOGY



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.

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

55 ans Âge moyen en début de maladie.

150 000 personnes dans le monde vivent avec la maladie.

1 200 décès par an.

WHO IS AR**SLA** ? 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

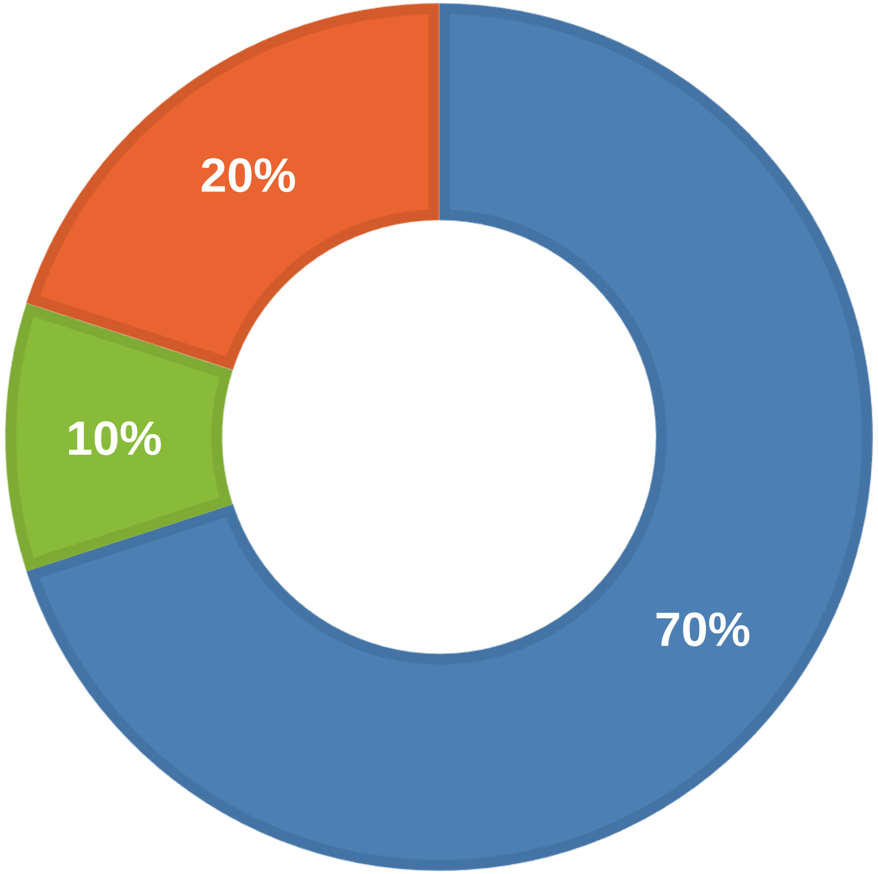
- 200 BEVEREAD CAREGIVERS

- 600 PROFESSIONNAL CAREGIVERS

THE RESULTS

1. How caregivers know us ?

- 🟦 From ALS center
- 🟧 From Internet
- 🟩 From another patient



THE RESULTS FROM FAMILY CAREGIVERS

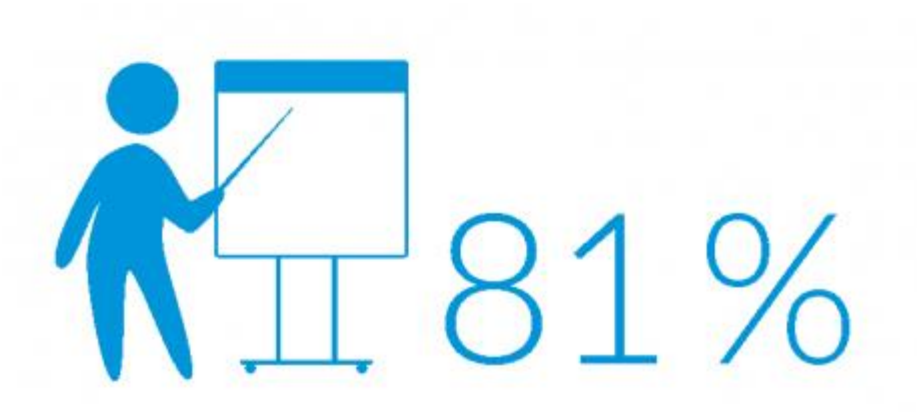
🟩 To find solution to take care better their patient

🟧 To find listening and talk with other cargivers

🟦 More information about the cure

■ To have respite

THE RESULTS FROM PROFESSIONNAL CAREGIVERS



- Learning specifity of ALS
- To be formed

We decided :

⇒ To renforce existing actions

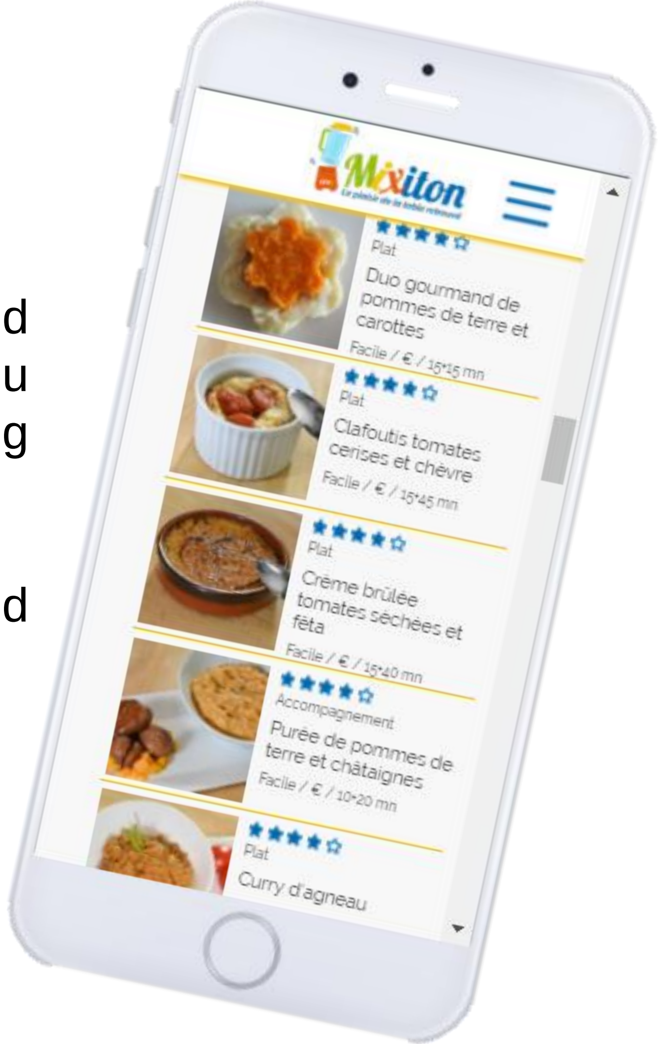
⇒To create new action

1. Mixiton

Le plaisir de la table retrouvé

- 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 cargiver find a solution by putting sugar and curcumin

- We launched 2 recipe competitions: one traditional recipe and another for celebration (Christmas, easter…)



Mixiton

Le plaisir de la table retrouvé

Plat
Duo gourmand de pommes de terre et carottes
Facile / € / 15+15 mn

Plat
Clafoutis tomates cerises et chèvre
Facile / € / 15+45 mn

Plat
Crème brûlée tomates séchées et féta
Facile / € / 15+40 mn

Accompagnement
Purée de pommes de terre et châtaignes
Facile / € / 10+20 mn

Plat
Curry d'agneau

2. Mixiton

Le plaisir de la table retrouvé

Cooking workshop every two months !

Animated by a caregiver and a cheaf 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


Maxiton

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

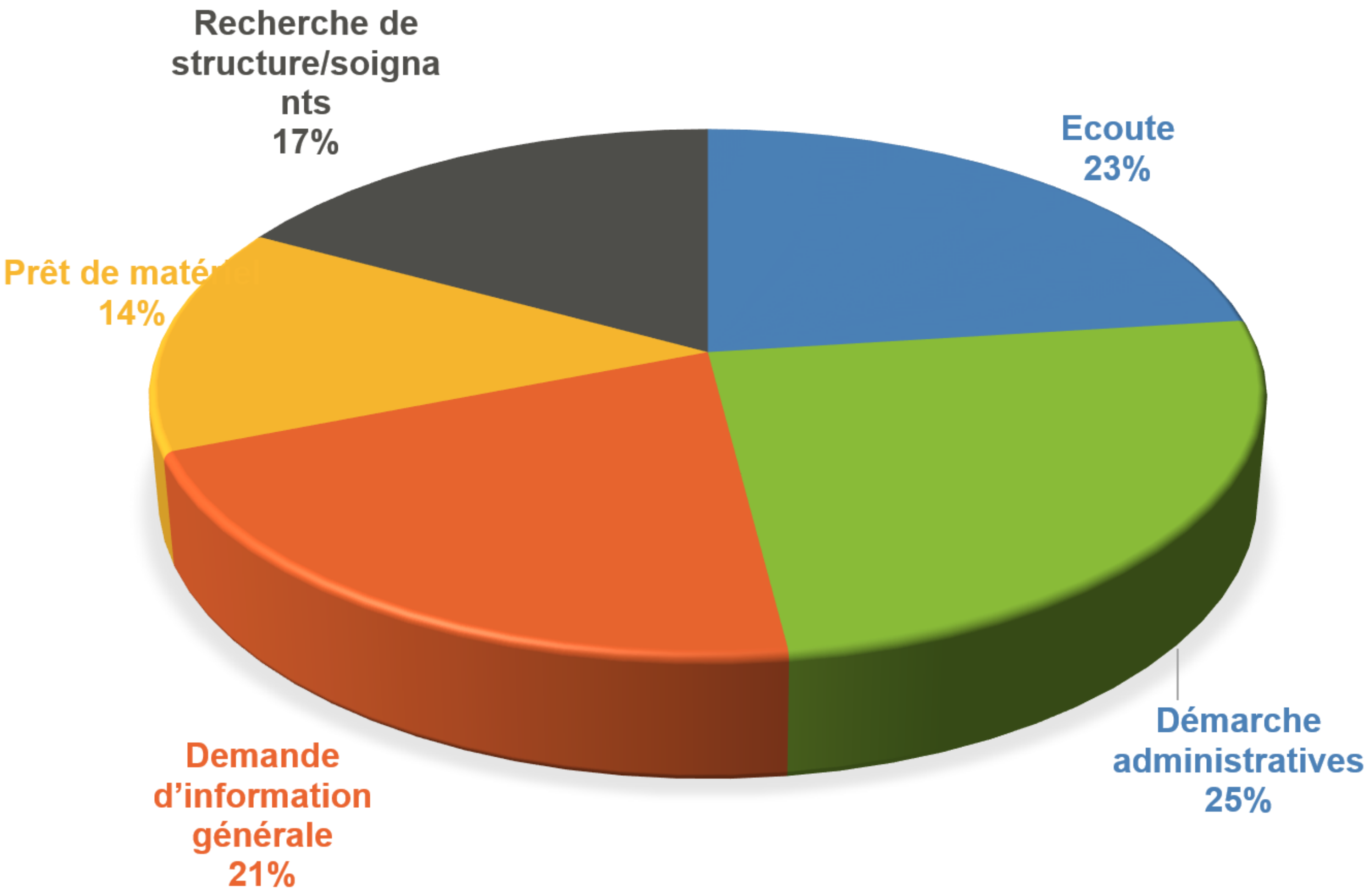
- Since 2 years, we training this volunteers how to listen , how use their own experience to be more empathic, how to work together with social worker. For example, il a person talk about technical question like research, the volunteers gives the call to one of the professional employees of the association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

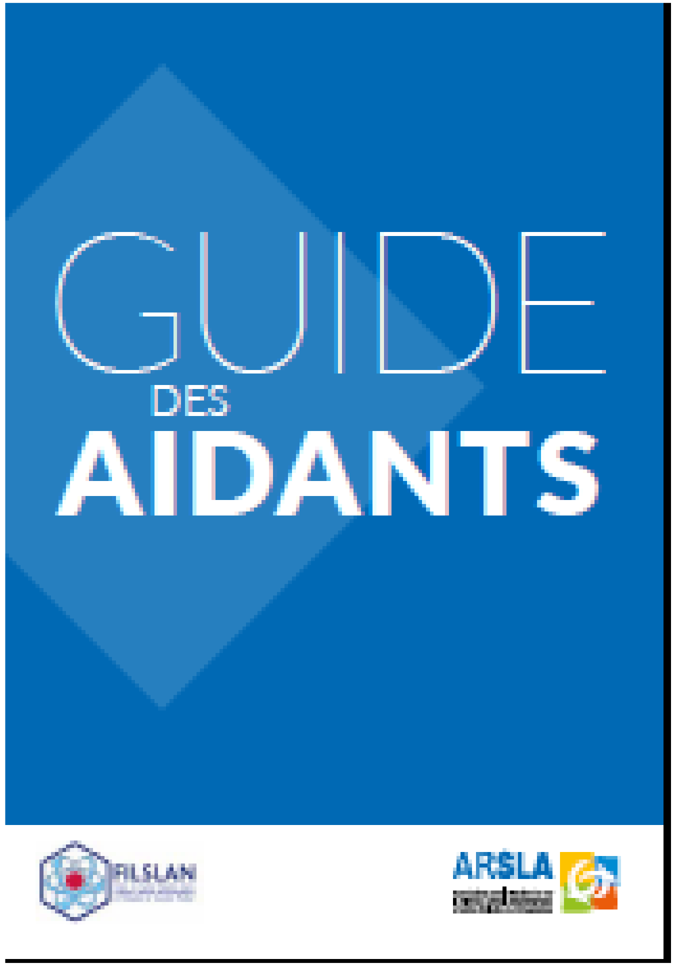
Help for adminsitratif process

Information about ALS, cure

Medical equipment

Information about research, clinical trials

4. A BOOK/ GUIDE


GUIDE
DES
AIDANTS

FILSLAN

ARSLA

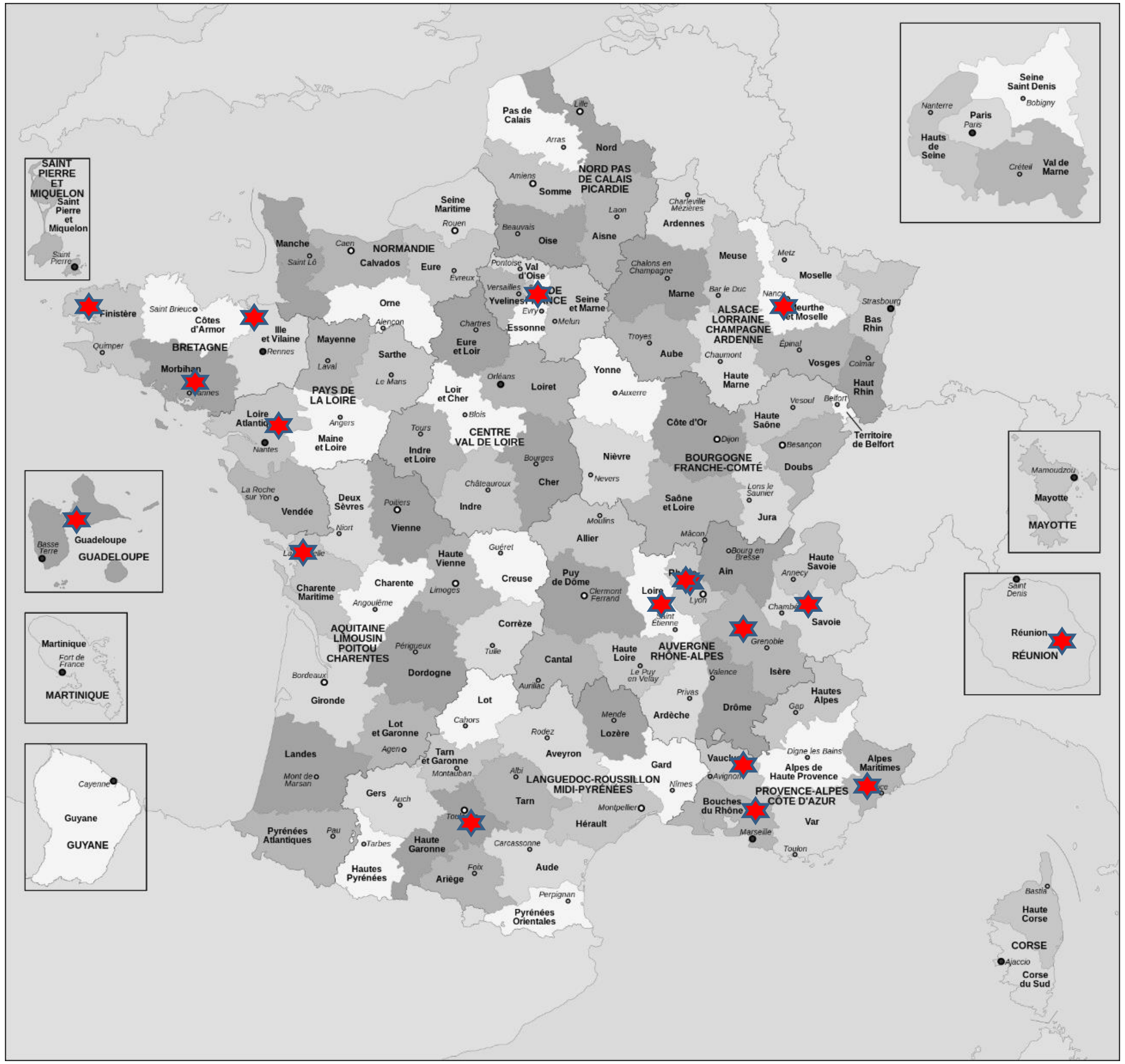
We have written a guide about what they have to do at each stage of the disease : since diagnosis to after the death because the caregiver stay alone without support

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 annonced the diagnosis. When the cargiver 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)

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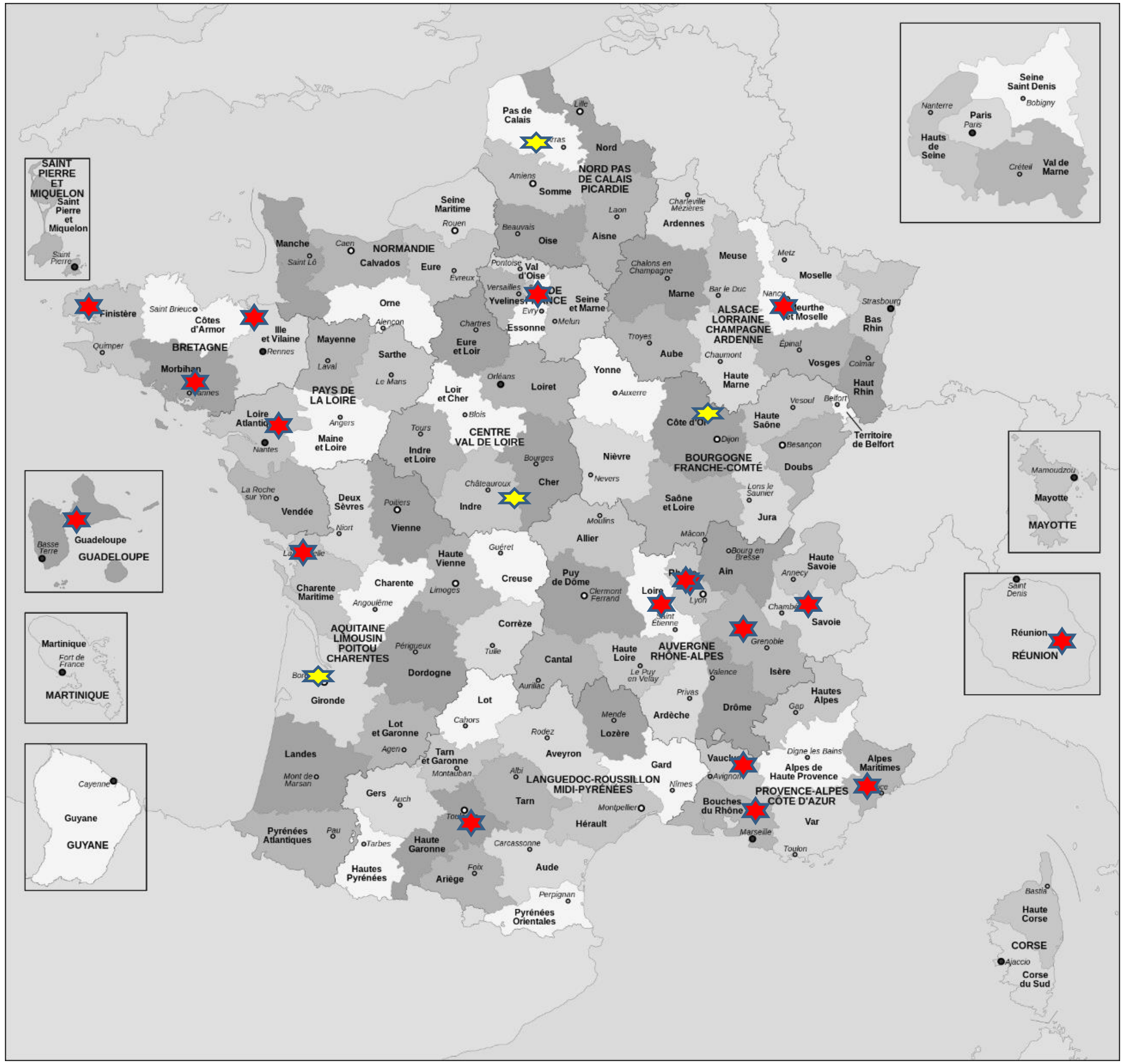

- 10 particpants maximum
- The psycologists have a big experience on neurodegentive desease
- In 2020, we'll create four new group

WE NEED YOU FOR THE NEXT STAPE

Mixiton

Cook, Mix,Play !

Thematic : world cuisine

Until 26 january 2020

Make its taste buds travel...

CARERS, ENRICH THE MIXITON, APPLICATION OF YOUR MIXED AND CHOPPED RECIPES

MORE INFORMATIONS : MIXITON@ARSLA.ORG

- We launche a new recipe competition, an international competition
- for all cargiver
- 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 choices the 30 most recipes which are submitted to the final jury, which will take place on avril

Step 3-
Jury final

This committee will consist of:

- **Patients**, because they are the first concerned
- **Caregivers**,
- **Profesional Health** (occupational therapist, nutritionnist…)
- **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

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