

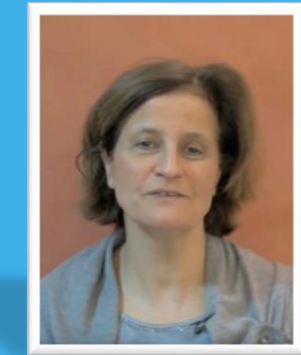
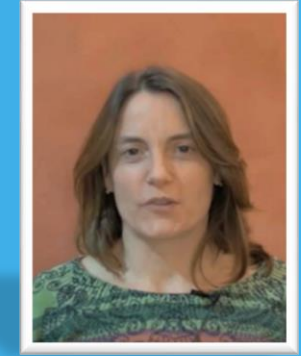


Association française  
Sclérose Tubéreuse de  
Bourneville

# The TSC burdens in France for patients and caregivers

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Research Conference  
on TSC and LAM  
LAMposium DC  
Regional TSC Conference





# Introduction : The survey

## The approach:

- A questionnaire inspired from surveys conducted in the UK, Australia and USA.
- Survey open to all patients with TSC, >15 yo and to their caregivers.
- Online survey on ASTB's website (from June 2016 to January 2017)

## Covered Issues:

Manifestation of TSC, accessibility to healthcare system and welfare, impact on education, impact on professional orientation, costs, impact on caregivers health, impact on the partners and siblings ....

## The survey design:

- mCQ based and open text comments
- Quantitative and qualitative



## Analysis:

Final report of 88 pages with numbers, comments and Interpellations when possible



## Numbers:

**1,5** years to conduct the study

**6** ASTB volunteers

**1** student

**1** consultant

# Summary

## ID card of the population that participated to the survey

- ✓ Patients and caregivers, who are they?

## TSC impact on patients

- ✓ Manifestations
- ✓ Autonomy
- ✓ Access to healthcare
- ✓ Access to welfare
- ✓ Education
- ✓ Professional orientation



## TSC impact on caregivers

- ✓ Costs
- ✓ Impact on professional life
- ✓ Impact on health
- ✓ Partners and siblings

## Research

- ✓ What are priorities for Research?

## Conclusion

- ✓ TSC in 4 words
- ✓ Next steps of the survey



# TSC population that participated to the survey

390 responders for 412 answers

5% of the TSC population in France (91% living in France)

## Gender



Women  
76 %



Men  
24 %

## Status



Caregivers  
67 %



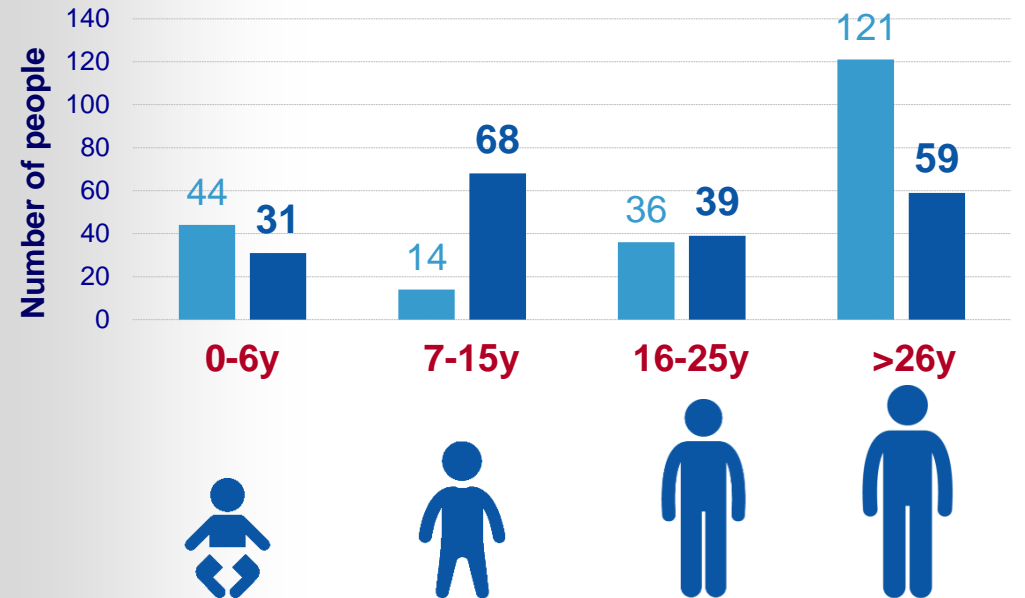
Patients  
29 %



Both patients  
and caregivers  
4 %

## Age and severity of the disease

slightly affected (52%)  
severely affected (48%)





# TSC impact on patients

- ✓ **Manifestation of TSC**
- ✓ **Autonomy**
- ✓ **Accessibility to healthcare**
- ✓ *Accessibility to welfare*
- ✓ **Education**
- ✓ **Professional orientation**



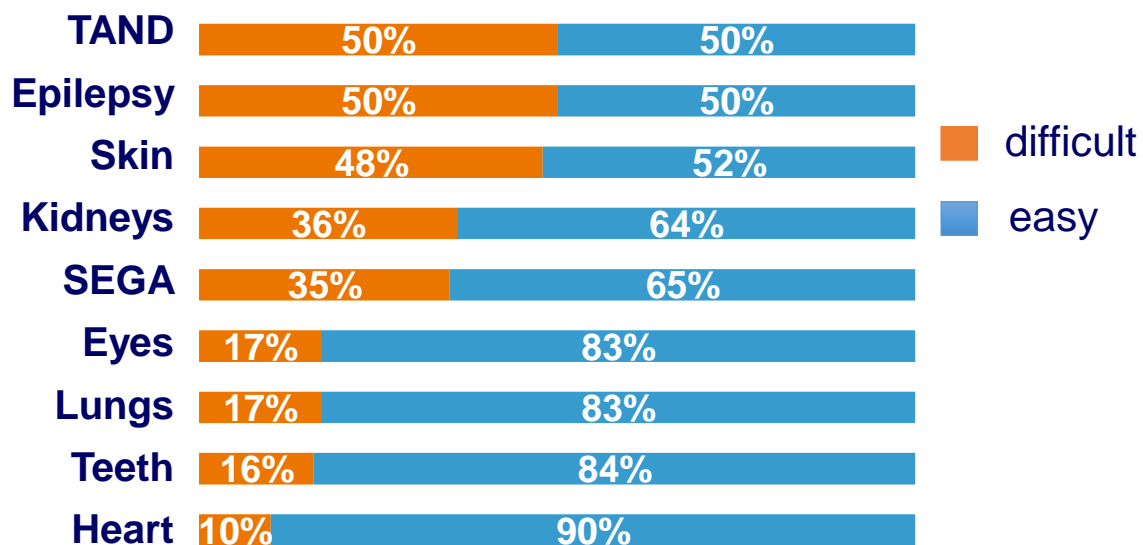


## TSC manifestations

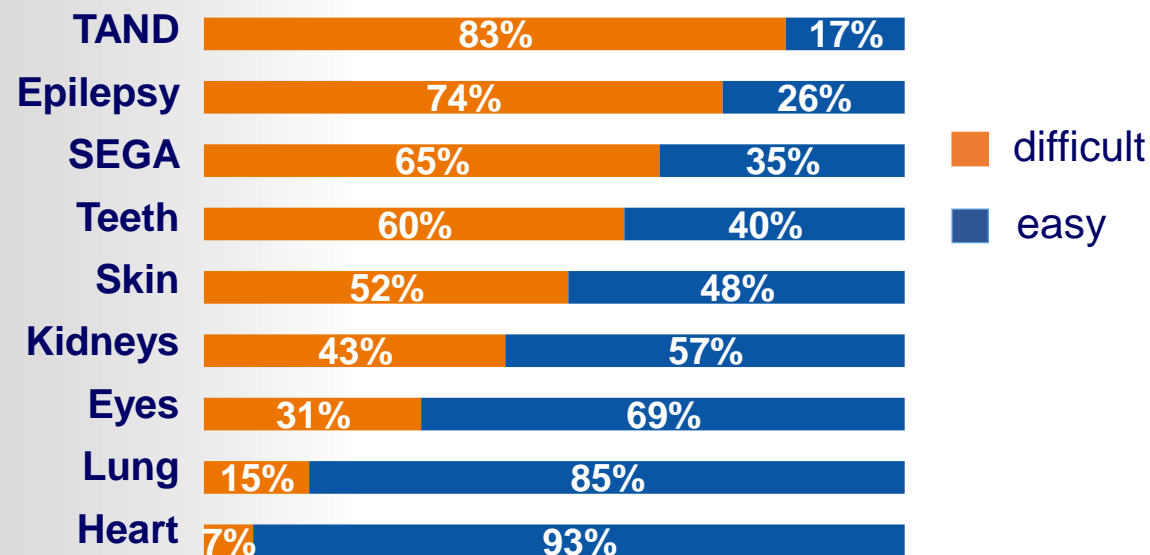
- ✓ 1<sup>st</sup> Skin problems : **96%** of responders
- ✓ 2<sup>nd</sup> For patients : Kidneys – **89%**  
For caregivers : Epilepsy – **93%**

### How manageable are they?

#### For slightly affected patients



#### For severely affected patients



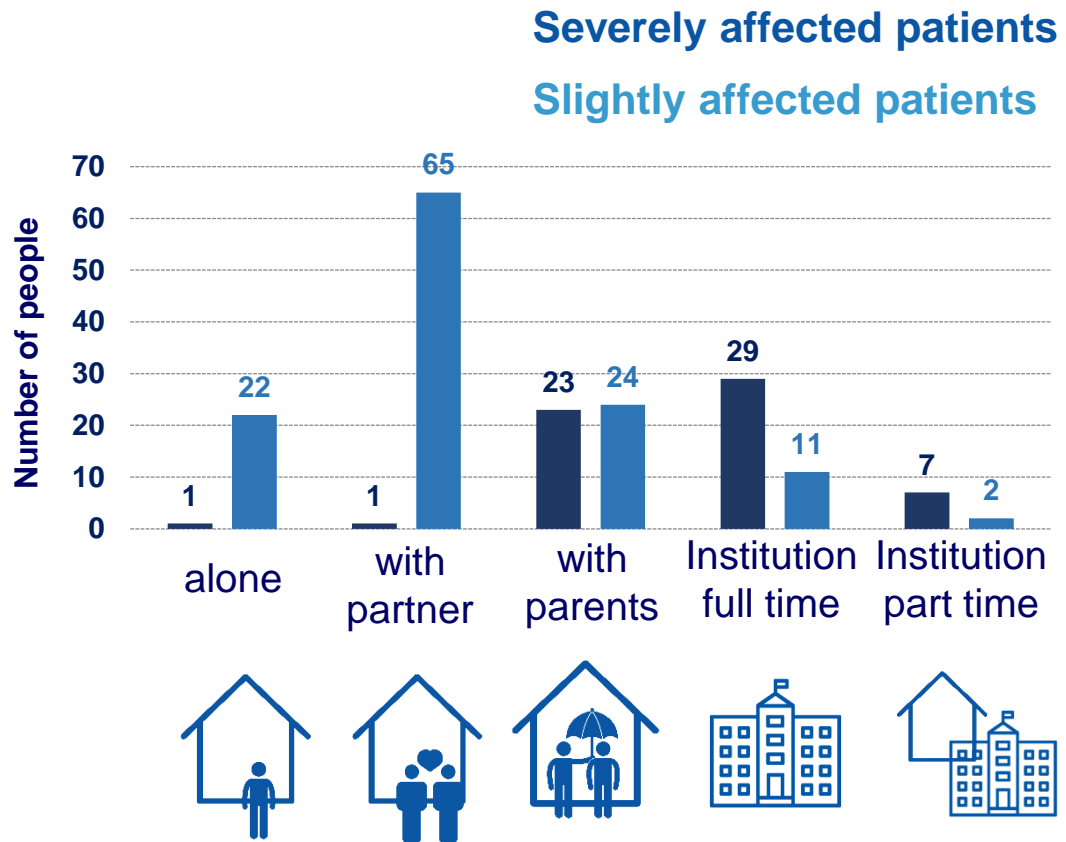
✓ TAND are difficult to manage for **75%**

- ✓ Under-diagnosed
- ✓ Under-considered
- ✓ Difficult to evaluate



## Degree of autonomy?

Where are they living (> 25 yo)



For patients older than 25 yo:



**50%**

are in a situation of dependence



- ✓ Solutions missing for young adults.
- ✓ Lack of suitable housing for disabled patients.



# TSC impact on patients

## Accessibility to healthcare?



> 50% having difficulties to find specialists

One patient needs on a regular basis **4** specialists:



up to **11** specialists for others



.... but no real coordinator



>5 consultations

>5 different days

>5 different locations



1 day consultation

1 single location

1 coordinator



- ✓ A TSC register and/or network is missing.
- ✓ Real needs for patients and doctors, to improve the multidisciplinary support of the disease.





### Impact on education?

For participants who attended school



50%

of their specific needs have not been taken into account during their schooling

- ✓ Significant gap between the needs of TSC patients and their support at school
- ✓ Rare implementation of adapted pedagogies

*“Learning problems often attributed to laziness but never linked to the disease, ...”*

*“[...] Abuse in school by other students who mocked [...] angiofibromas on my face.”*





## Impact on Career?

No access to a professional activity for :



**95%** of severely affected adult

**18%** of slightly affected adult

They must find an alternative occupational activity and additional financial resources.

Amongst patients, who have or have had a professional activity,



**53%** had their career affected by TSC

**22%** lost their jobs due to TSC



- ✓ How to set up specific support for educational and professional guidance?

# TSC Impact on caregivers

- ✓ **Costs**
- ✓ **Professional life**
- ✓ **Health**
- ✓ **Partners and siblings**





## Impact on caregiver's professional life?



**76%** of caregivers reported impact

with

**36%** had to reduce their working time

*“I stayed 10 years at home and when I returned to the labor market, I never found a permanent contract, ... Since then, I have been in a precarious situation.”*



✓ How to help caregivers on their professional life – to avoid loss of income and resulting isolation?



# Impact on caregiver's health?



64%

caregivers reported suffering from anxiety

17%

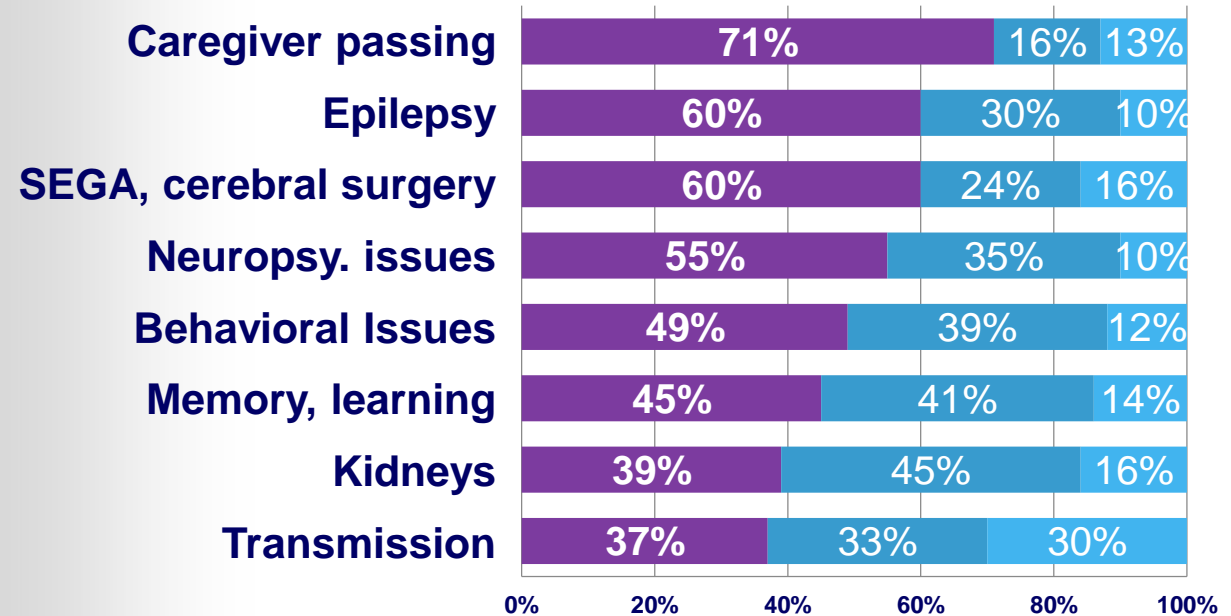
being treated for depression



✓ What about the psychological support of caregivers?

# Sources of fear or stress for the caregiver

- Important stress or fear
- Moderate stress or fear
- No stress or fear





# Patient's fate without the caregiver.

problematic for  
**87%**  
of the caregivers



*“I don't know where my daughter is going to live when an adult... Should we keep her at home? Do we need to place her in an appropriate institution?.....”*



How to improve the situation and reassure caregivers on the fate of the patients after their passing?



- ✓ Solutions missing for young adults.
- ✓ Lack of suitable housing for disabled patients.

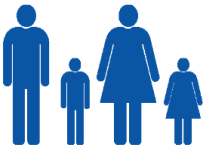


### Partners and siblings?



73%


reported that TSC had an impact on their relationship



71%


of siblings are impacted by TSC

- personal choice
- future
- personality
- relationship at school.....



*“My daughter was 6 when her sister with TSC was born. I think we have [...] set her aside. She certainly suffered.*

*[She] sometimes suffers from the rejection of her sister at school.”*



✓ Psychological support for the family is needed to bear up the multiple trauma generated by the disease.

What are the  
priorities for TSC  
research?







**If you could choose one topic for researchers to focus on over the next 5 years?**

**25% to suppress epilepsy**

**23% avoid TSC transmission**

**20% to suppress TAND**

**8% eliminate tumors**

**7% eliminate facial angiofibromas**

**others ...**



# Conclusion

## TSC in 4 words :

- ✓ Isolation
- ✓ Complexity
- ✓ Unpredictability
- ✓ Never Ending

Proper care with competent people (medical, academic, psychological), as well as the set-up of adapted institutions, would make a great difference. The stress of the patient and his entourage would also drop considerably.

## Next steps :

- ✓ Spread and share the data
- ✓ White Paper

Raise awareness on gaps and troubles patients and their caregivers suffer during their journey

Make materials available to speak on behalf of patients and caregivers

Make proposals to improve care and life

- ✓ Publication





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The result of the survey carried out by the ASTB  
association is available in its entirety at:  
[contact@astb.asso.fr](mailto:contact@astb.asso.fr)

