

# aHUS Patient Input Program – Wave 3

## PRESENTATION OF RESULTS

### KEY FINDINGS - FINAL

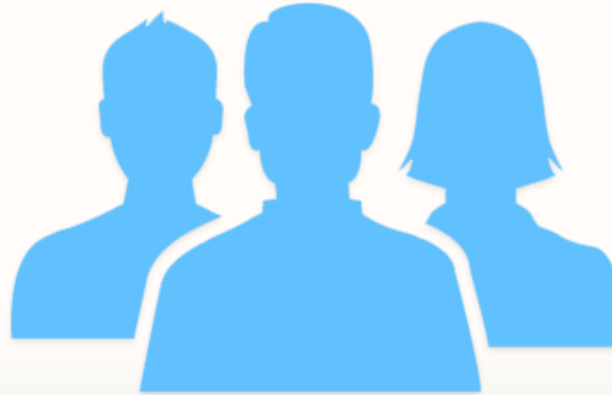
Prepared for:



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October 30, 2017



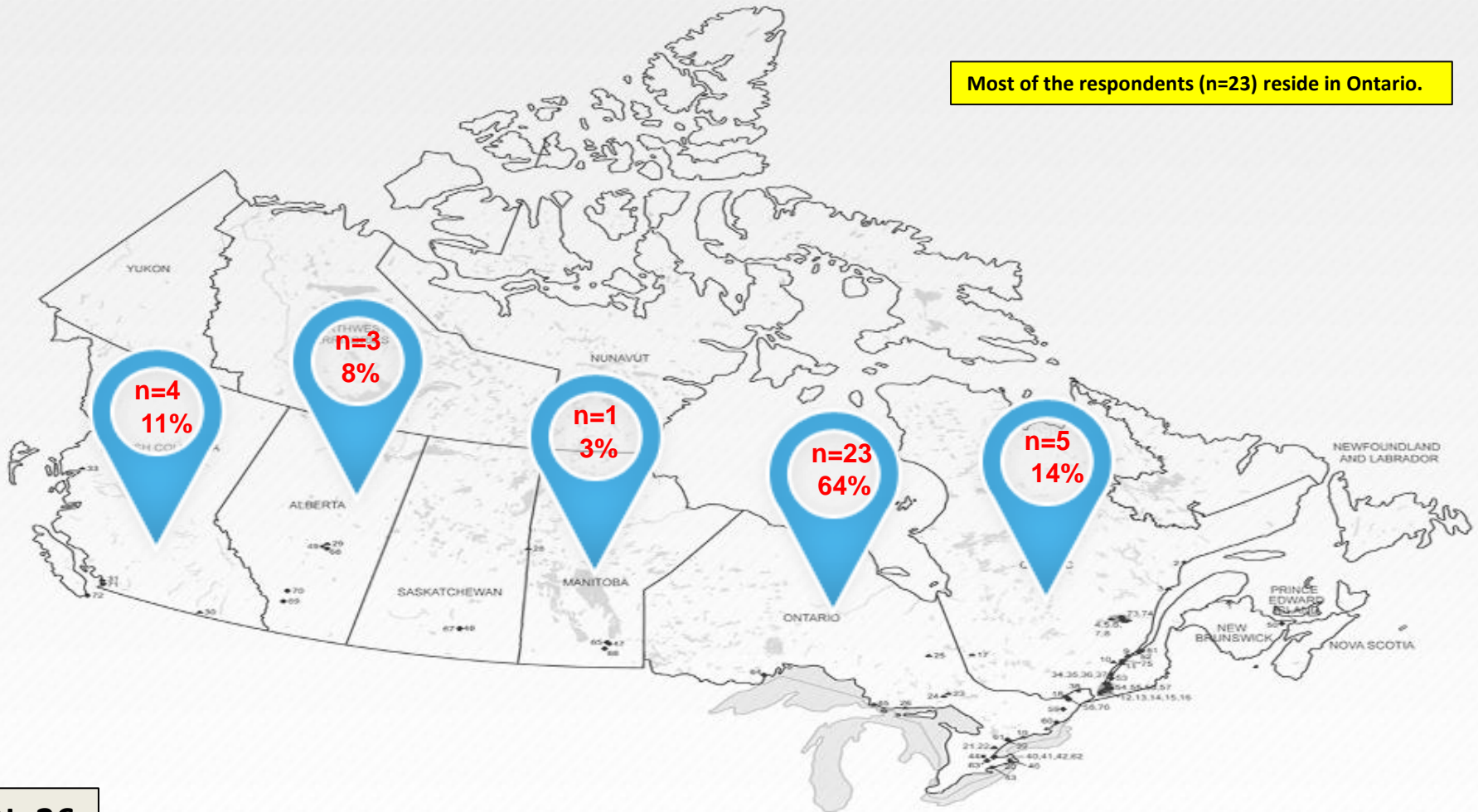
## RESPONDENT PROFILE

Note: Figures in all Tables/Charts are percentages unless otherwise noted

# Province



Most of the respondents (n=23) reside in Ontario.



N=36

# Age



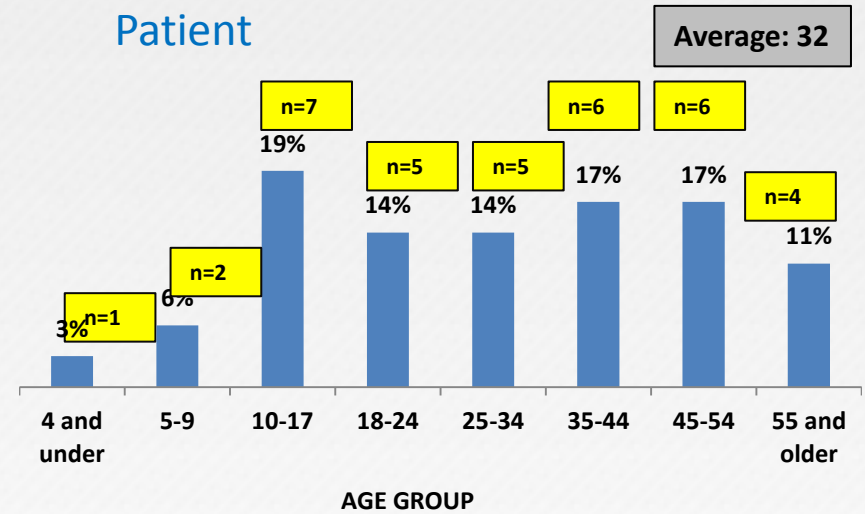
Patients average 32 years of age. Ten patients are under 18 years of age while ten patients are 18-34 years of age. Sixteen patients are 35 years of age or older.



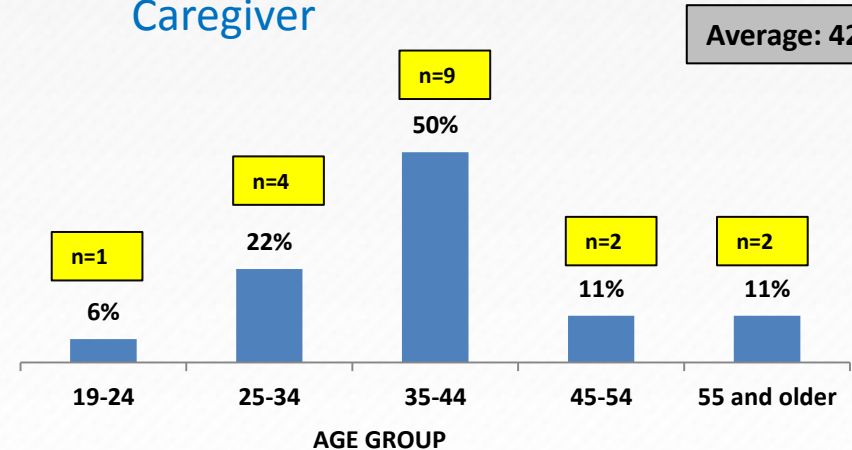
Caregivers average 42 years of age. A majority of the caregivers (n=15; 83%) are 25-44 years of age.

N=36

## Patient



## Caregiver



# Gender



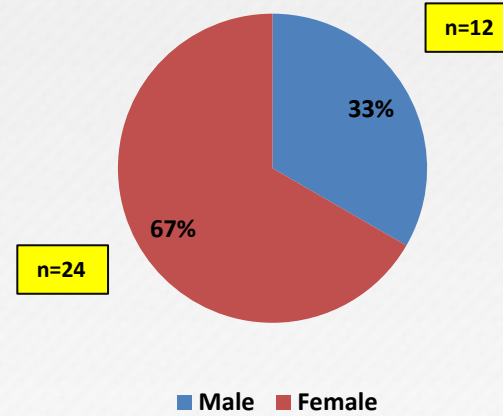
A majority of the patients included in this research are female (n=24; 67%).



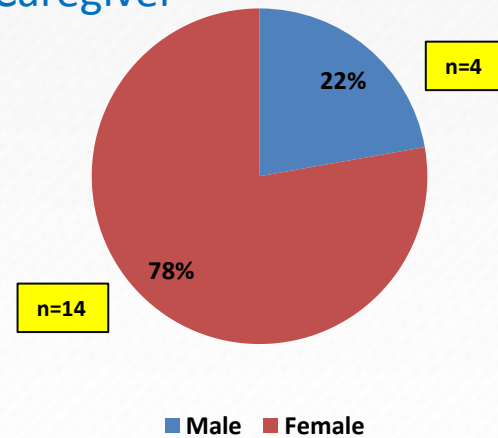
A majority of the caregivers participating in this research are female (n=14; 78%).

**N=36**

## Patient

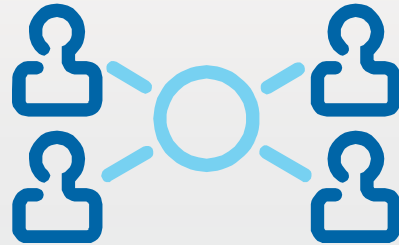


## Caregiver



# Key Findings

## New Discussion Areas



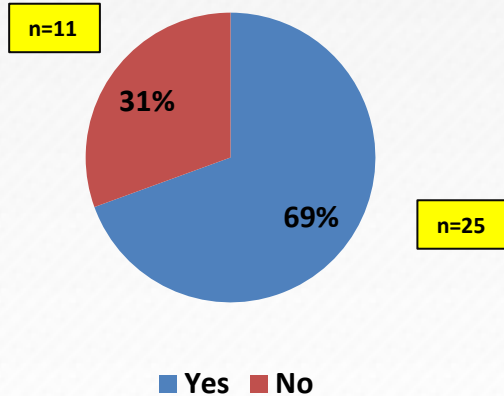
# PATIENT JOURNEY



Have you contacted another foundation related to your disease?  
What other foundations have you contacted? (Multiple response)

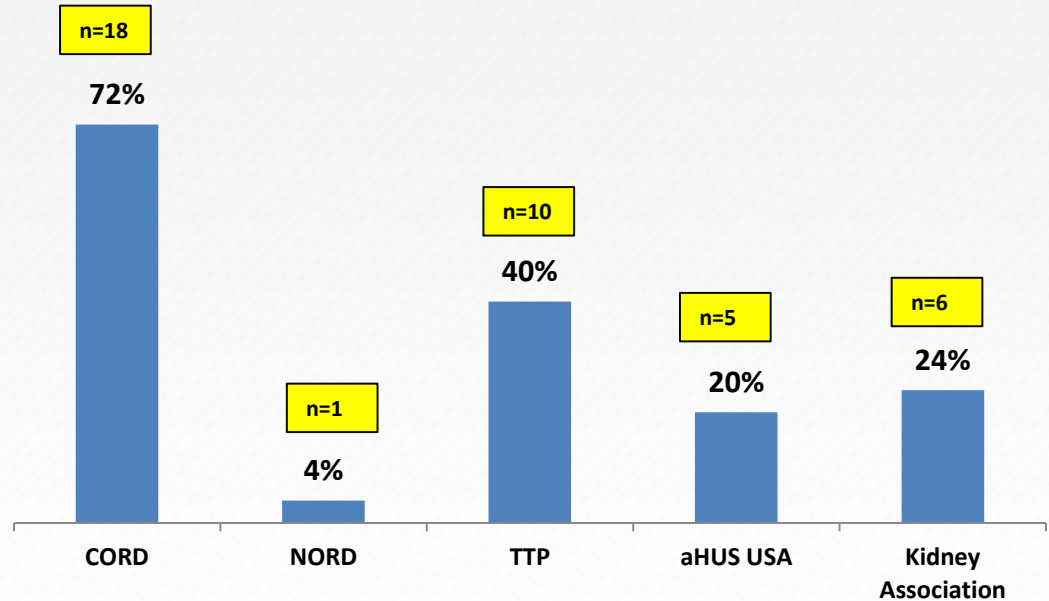
- It is common for patients/caregivers to contact foundations other than aHUS Canada to find information related to their disease.
- CORD is the most likely other foundation contacted about aHUS.

Incidence of Contacting Another Foundation About aHUS



N=36

Other Foundations Contacted About aHUS



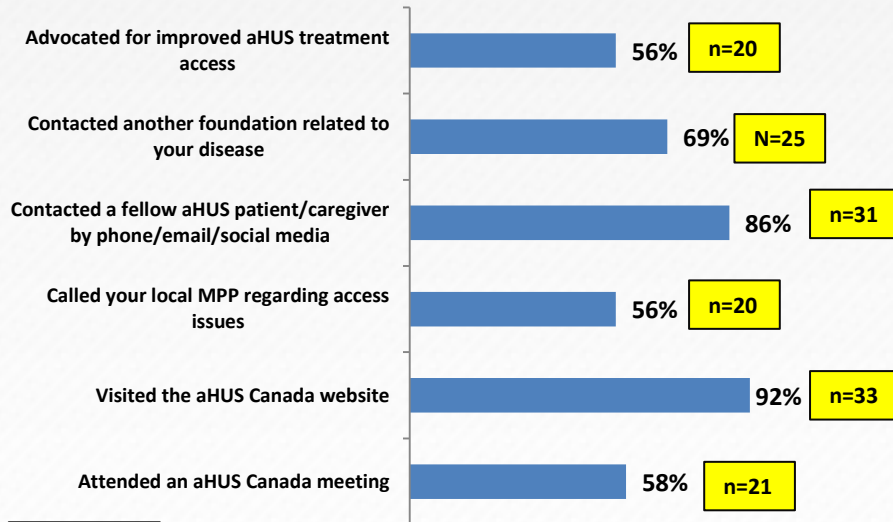
# PATIENT JOURNEY



Which of the following have you done in the past three years? (Multiple response)  
Which of the following have you done in the past six months? (Multiple response)

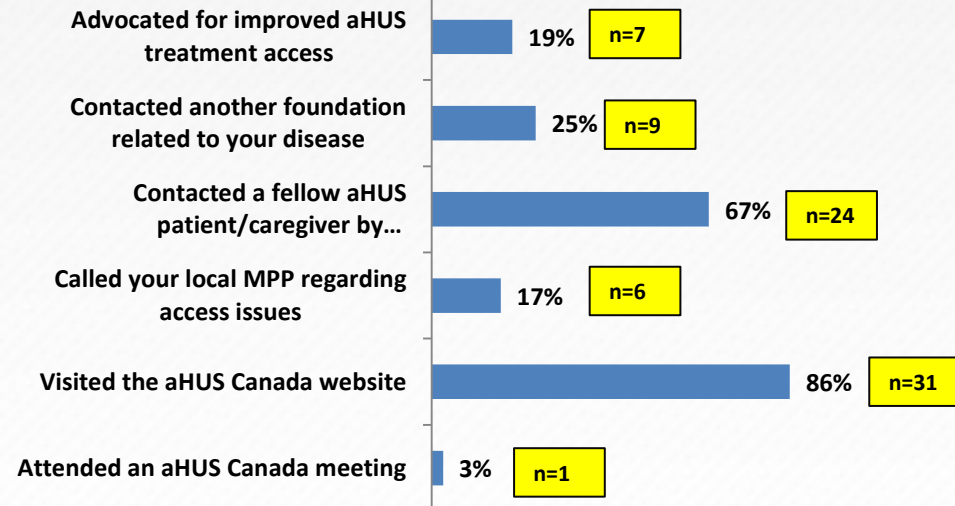
- Visiting the aHUS Canada website and contacting other aHUS patients/caregivers by phone/email/social media are very common activities. A majority of patients/caregivers have attended an aHUS Canada meeting in the past.
- Advocacy efforts are not as strong – particularly in the past 6 months – low rates of MPP contact.

## Activities In The Past 3 Years



N=36

## Activities In The Past 6 Months





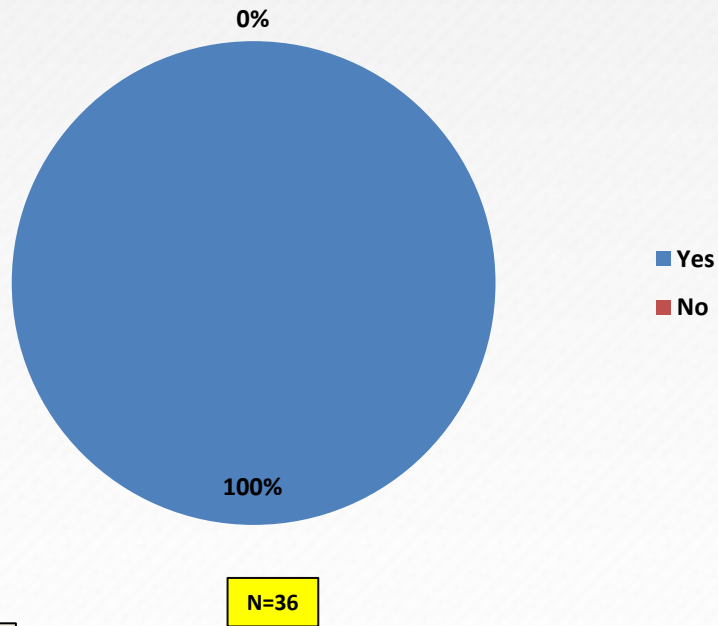
# PATIENT JOURNEY



Are you aware that aHUS is a genetic disease?  
Have you undergone genetic testing?

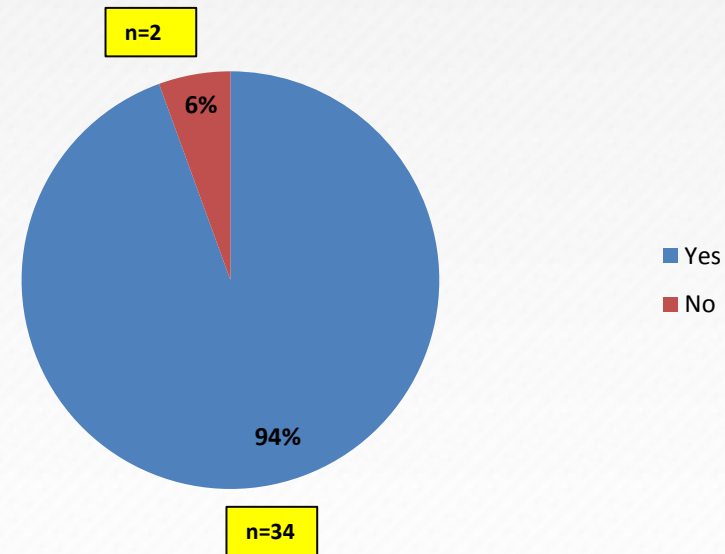
- All the patients/caregivers are aware that aHUS is a genetic disease.
- All but two of the patients has undergone genetic testing.

Awareness that aHUS is a Genetic Disease



N=36

Incidence of Undergoing Genetic Testing



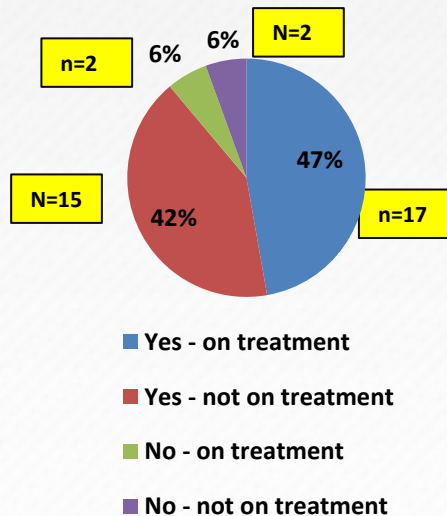
# PATIENT JOURNEY



Has your outlook changed from the time you were originally diagnosed to the present?  
 How has your outlook changed? Why has your outlook not changed? (Multiple response)

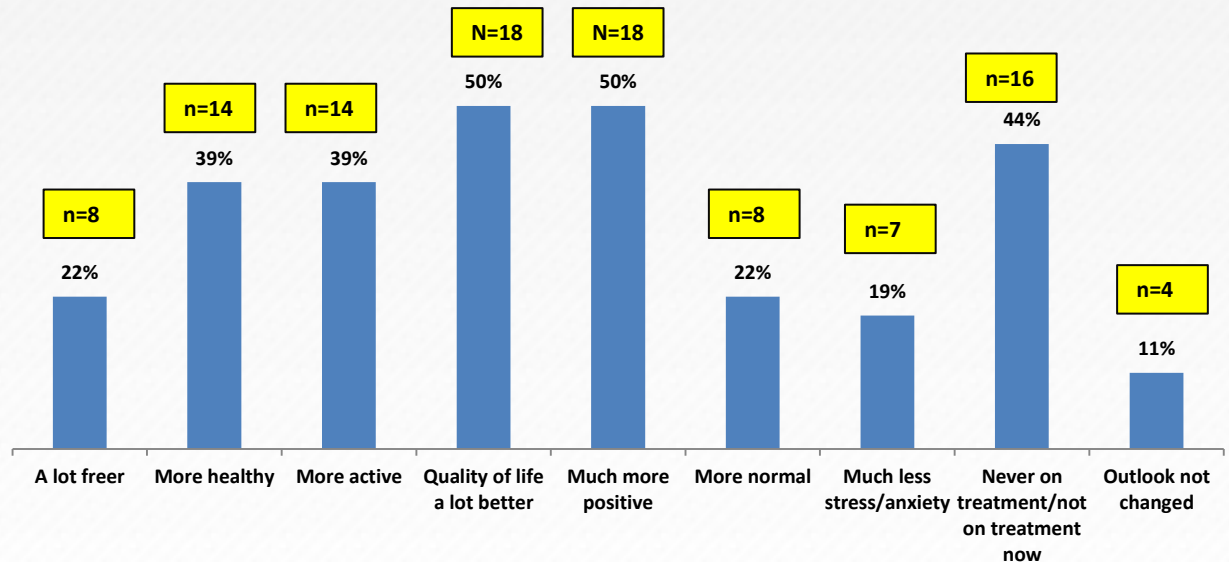
- Most patients/caregivers are ‘now a lot more positive’ than they were at the point of diagnosis. Patients have a ‘much better quality of life’ and are ‘more active’, ‘healthier’ and ‘have ‘much less stress/anxiety’.
- Two patients have the same outlook now as when diagnosed – ‘positive – because of Soliris’ while two patients not on Soliris are still disappointed with access issues.

Whether Outlook Has Changed Since Original Diagnosis



N=36

Manner in Which Outlook Changed Since on Soliris Treatment – Top Mentions



# PATIENT JOURNEY

How has Soliris (eculizumab) changed your life? UNAIDED  
How life changed? UNAIDED  
Reactions to Soliris (eculizumab)?

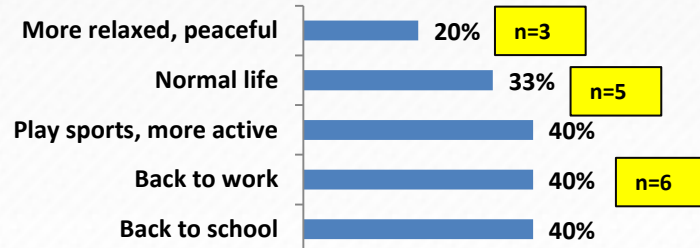


- All the patients on eculizumab (N=15) consider their treatment to be **'life changing/restoring'**
- Eculizumab allows these patients and their families to return to a state of 'normalcy' – 'going back to school', 'going back to work', 'playing sports' – 'being active again'
- Their lives have been changed for the better

Whether life has changed for the better since eculizumab introduced

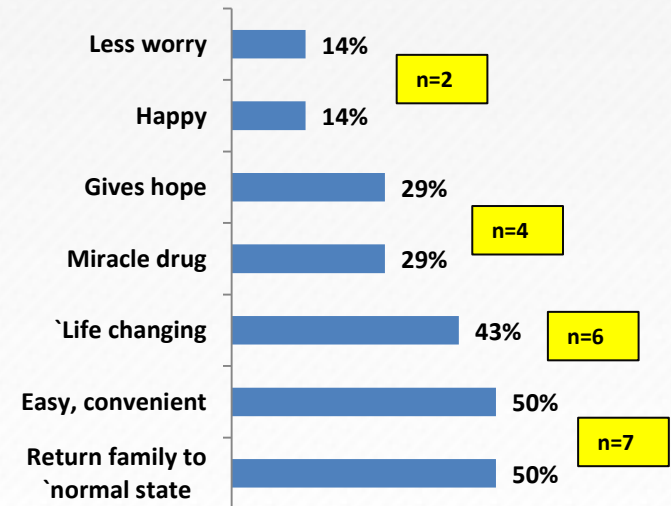
YES – 100%

How Life Changed



N=15

Reaction to eculizumab



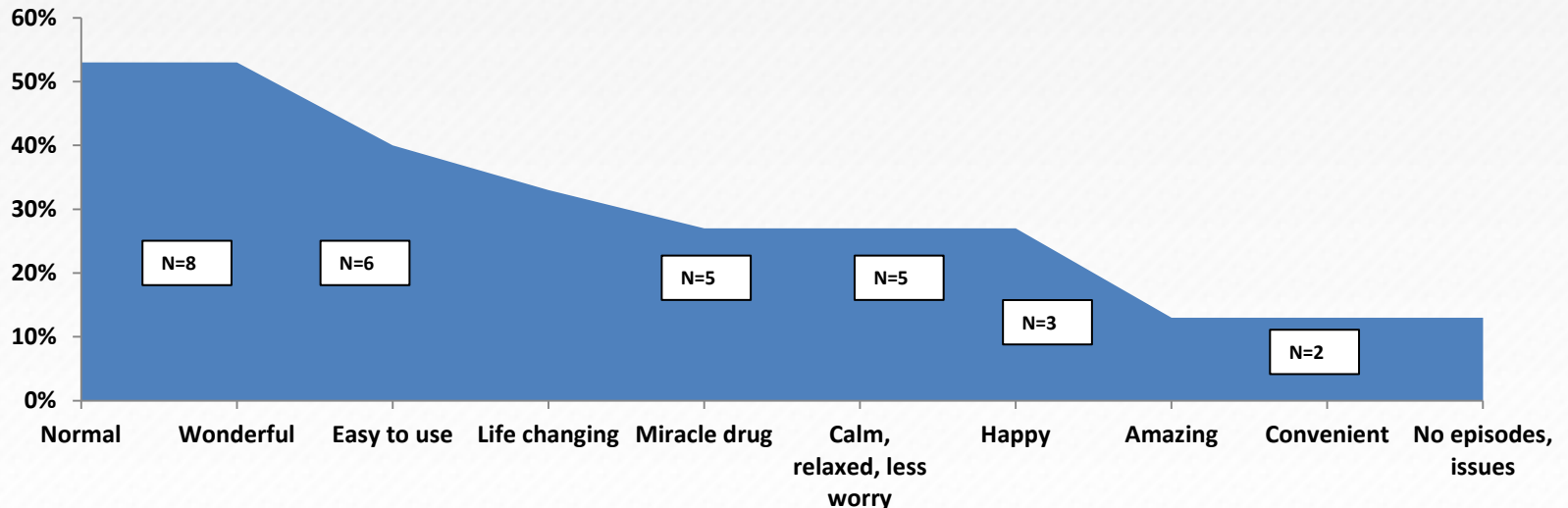
# PATIENT JOURNEY

What words would you use to describe your Soliris (eculizumab) treatment?



•Key words used to describe the impact of eculizumab treatment include: **'wonderful', 'easy to use', 'life changing', 'miracle drug', 'calm, relaxed, no-less worry' and 'convenient'**

Words used to describe the impact of Soliris (eculizumab) treatment



N=15

# PATIENT JOURNEY

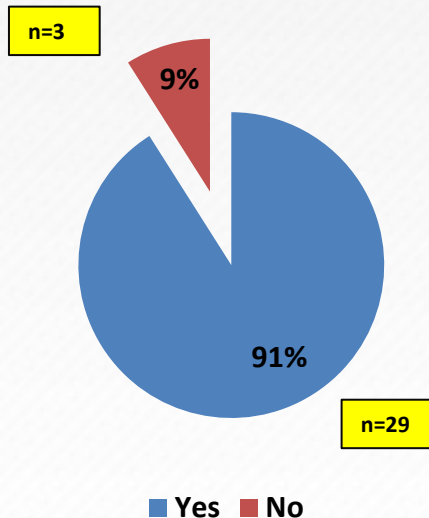


Are you familiar with a patient support program called ONESOURCE?

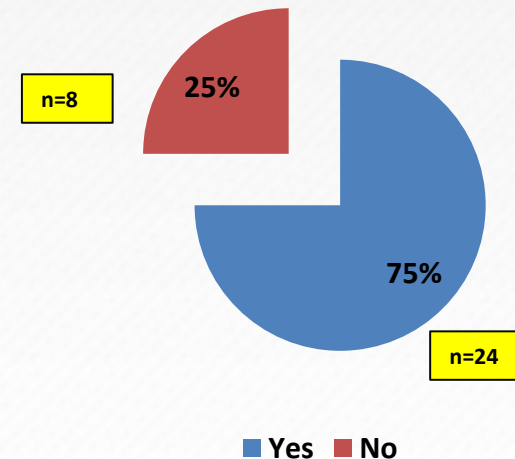
Has ONESOURCE helped with your reimbursement, that is, trying to help you gain access to eculizumab through private and public payers?

- Almost all the respondents (29 of 32) are **aware** of the patient support program – ONESOURCE
- Most patients/caregivers are **aware** that ONESOURCE helps with reimbursement – the paperwork required to apply for – gain access to eculizumab

Awareness of ONESOURCE



Awareness that ONESOURCE helps with reimbursement



N=32

# PATIENT JOURNEY

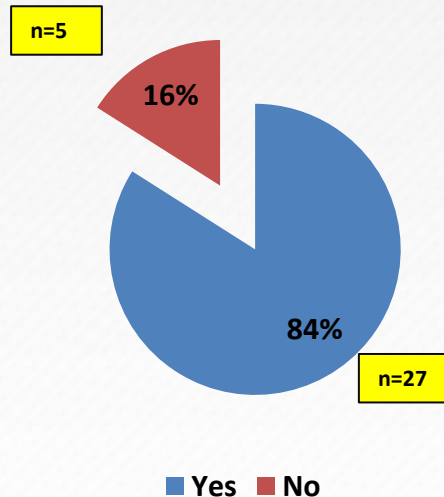


Do you keep up to date with new clinical data related to aHUS and its treatment?

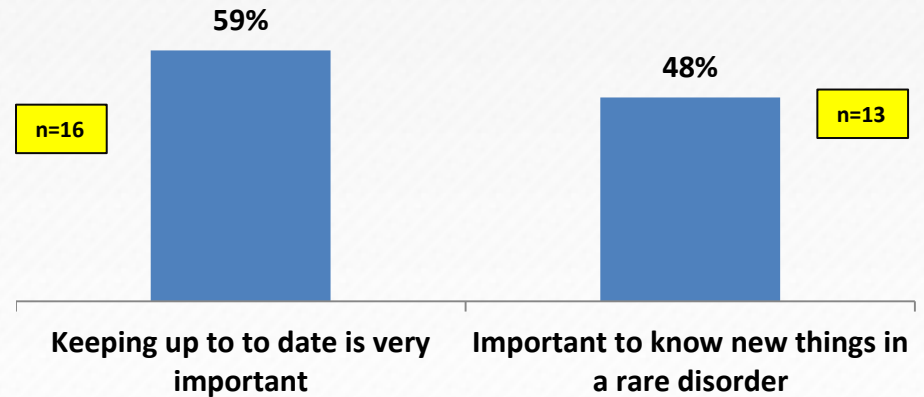
Why do you keep up to date with new clinical data related to aHUS and its treatment? UNAIDED

- Most patients/caregivers stay up to date with **new** clinical data related to aHUS
- These patients strongly believe that it is important 'to keep up to date' in a rare and 'new' disorder

Whether keep up to date with new clinical data



Reasons for keeping up to date with new clinical data (N=27)



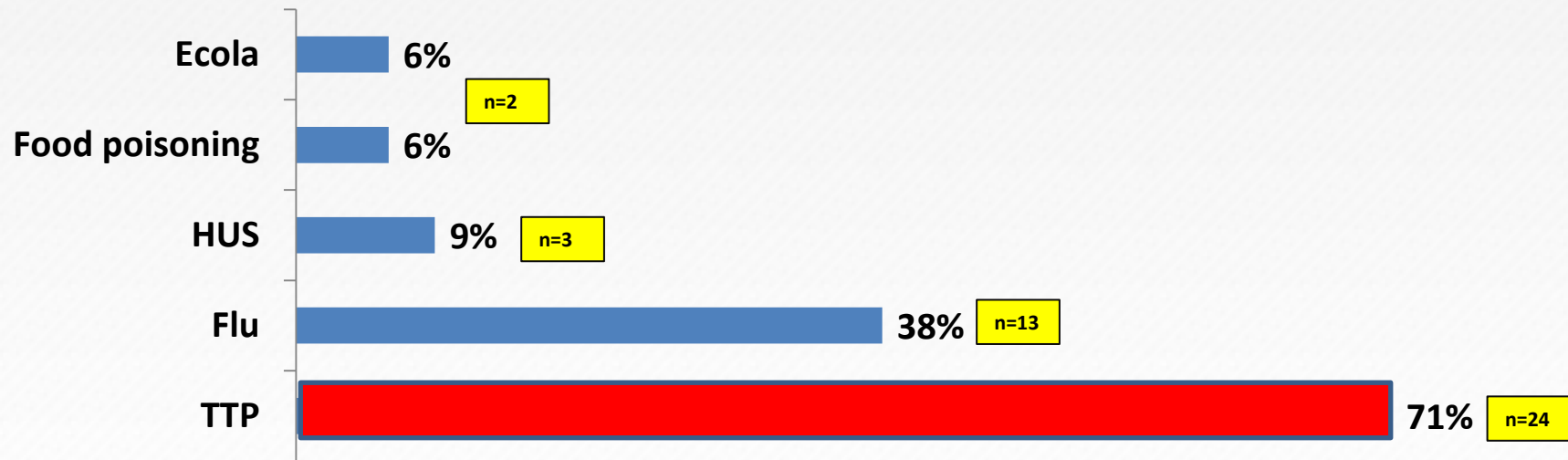
N=36

# PATIENT JOURNEY



What condition/disorder were you suspected of having/diagnosed with prior to being diagnosed with aHUS by your doctor? UNAIDED

- In a majority of cases patients were diagnosed with TTP before the correct aHUS diagnosis was made



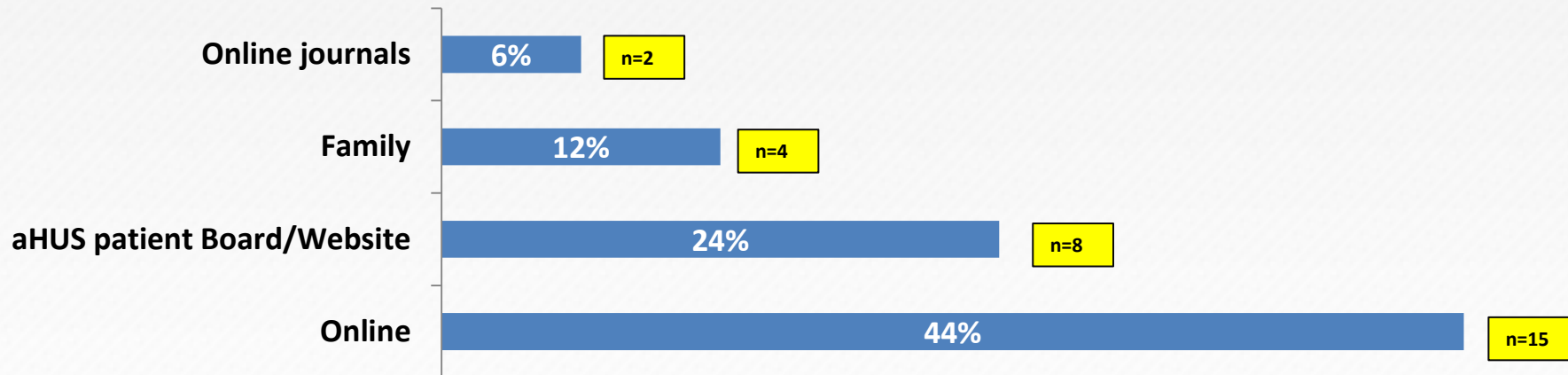
N=36

# PATIENT JOURNEY



Which of these resources do you find most useful? UNAIDED

- **Online searches and the aHUS Patient Board/Website are considered to be the two most useful resources available to patients and their families - outside of the medical community**



N=36