



# DIAGNOSIS AND TREATMENT:

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STANFORD PANS  
PROGRAM

# Presenting Symptoms: Who do you see for help?



Fever  
Sore throat  
Frequent  
urination  
Rash  
Headache  
Earache  
Motor dysfunction  
Chorea

Tics  
Behavior  
Problems

Obsessions  
Compulsions  
Anxiety  
Hyperactivity  
Mood  
Rage  
Cognitive changes  
School trouble

# Evaluation and Treatment



Infection work-up  
Infection treatment  
Immunological therapy  
Steroids  
NSAIDs  
Other Immunotherapy

Facilitate work-up  
Facilitate treatment  
Family training  
Family support  
Behavioral interventions  
Cognitive Behavior Therapy  
Psychiatric medication  
School Coordination

# PSYCHIATRIC AND BEHAVIORAL INTERVENTIONS

- Do not treat the underlying process (much)
- Require individualization
- Many variables change at once
- Psychotropic medication responses are atypical
- Require adjustment over illness course
- Require multidisciplinary approach
- Derive from evidence-based treatments

# MAKING CLINICAL DECISIONS



- Preferred
  - Evidence-based medicine
  - Shared decision-making between family and medical team
- Other ways to make medical decisions
  - Clinical consensus
  - Snap judgments- anchoring on a specific symptom
  - Stereotyping
  - Weighing too much on recent experience
  - Ignore symptoms that don't fit with usual pattern
  - Stopping searching if find an answer
  - Denial of uncertainty (Makes matters clearer, Makes action possible)
  - May stop searching once they believe something is found

# HOW DO CLINICIANS FEEL?



- Clinicians want to treat patients successfully
- Clinicians may not like difficult patients (even though they may not realize it)
- Clinicians are uncomfortable treating outside the area of their discipline
- Clinicians are generally rushed
- Clinician to clinician communication is difficult to achieve because of
  - Time constraints
  - Lack of reimbursement

# CLINICIANS CAN MAKE MISTAKES

- Limitation of current medical knowledge
- Incomplete or imperfect mastery of available knowledge
- Denial of uncertainty
  - Makes matters clearer
  - Makes action possible
- May stop searching once they believe something is found



# CLINICIANS' DISLIKES CAN AFFECT CLINICAL TREATMENT

- Clinicians may dislike “Medical” patients with psychiatric symptoms
  - Maybe seen as neurotic, delusional, cloying, untruthful
  - May be disliked if seen as anxious or neurotic
  - May cut them off during histories
  - Get short shrift
  - May receive “convenient” diagnoses and treatments
- Clinicians’ dislike of uncertainty can lead to
  - Premature pronouncement of “definitive” answers
  - Dismissal





# CLINICIANS' DILEMMAS AND QUANDRIES



- Should one not see particular patients because of uncertainties?
- Should one treat outside one's specialty?
- To whom should one refer patients?
- Should one reinvent oneself as an expert in a new field?
- Should one use treatments that are “off label”?

# QUESTIONS FOR FAMILIES AND PHYSICIANS



- Treat if syndrome criteria not met?
- Who is treating physician?
- Which antibiotic? How long?
- ?Steroids, NSAIDs, tonsillectomy, IVIG, plasma exchange?  
“Alternative” treatments?
- How can one get physicians to coordinate care?
- What about family members warrants consideration?
- Immunization
- How to get school accommodations and which?
- How to get insurance to pay for treatment?

# Sydenham Chorea to Rheumatic Fever to Group A Strep to PANDAS

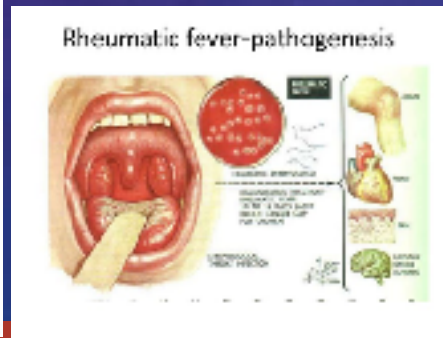


1685

1830

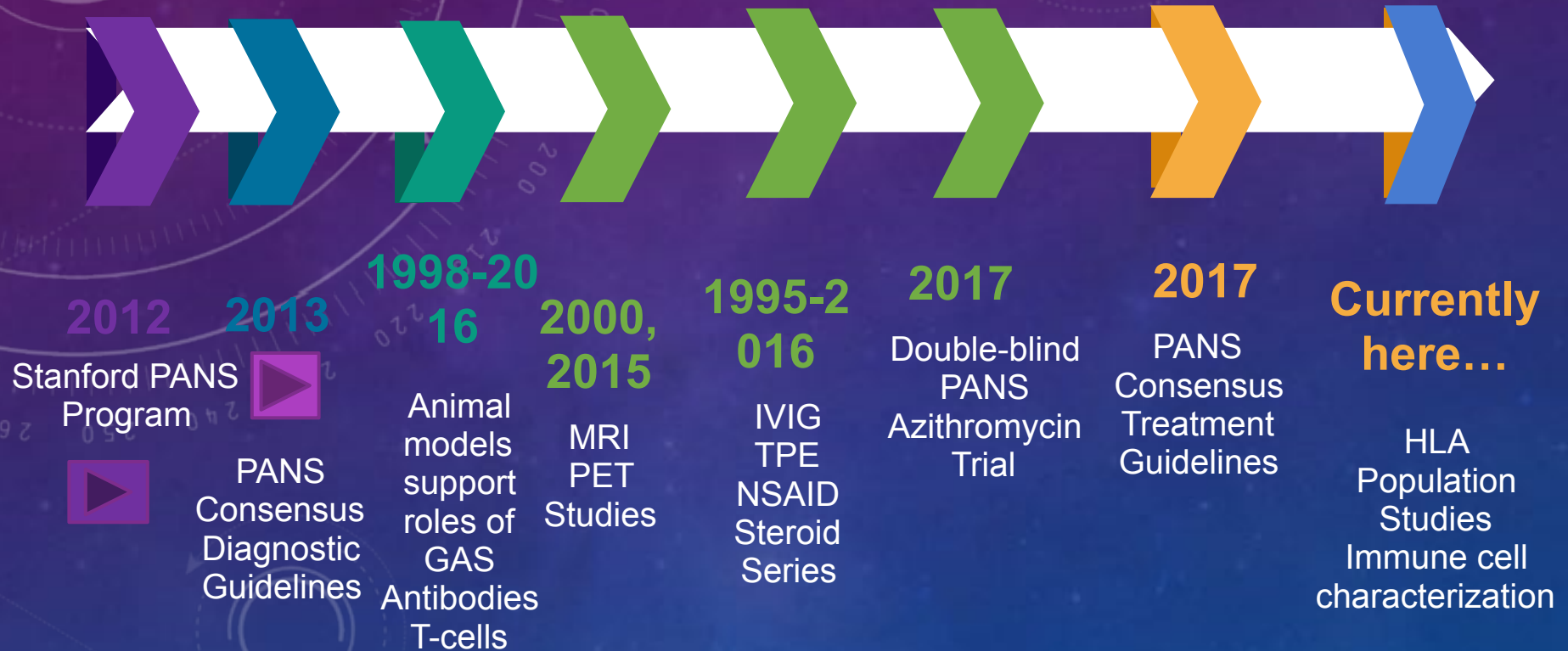
1928

1998



Early Onset OCD  
PANDAS

# PANDAS and PANS



# STANFORD PANS PROGRAM

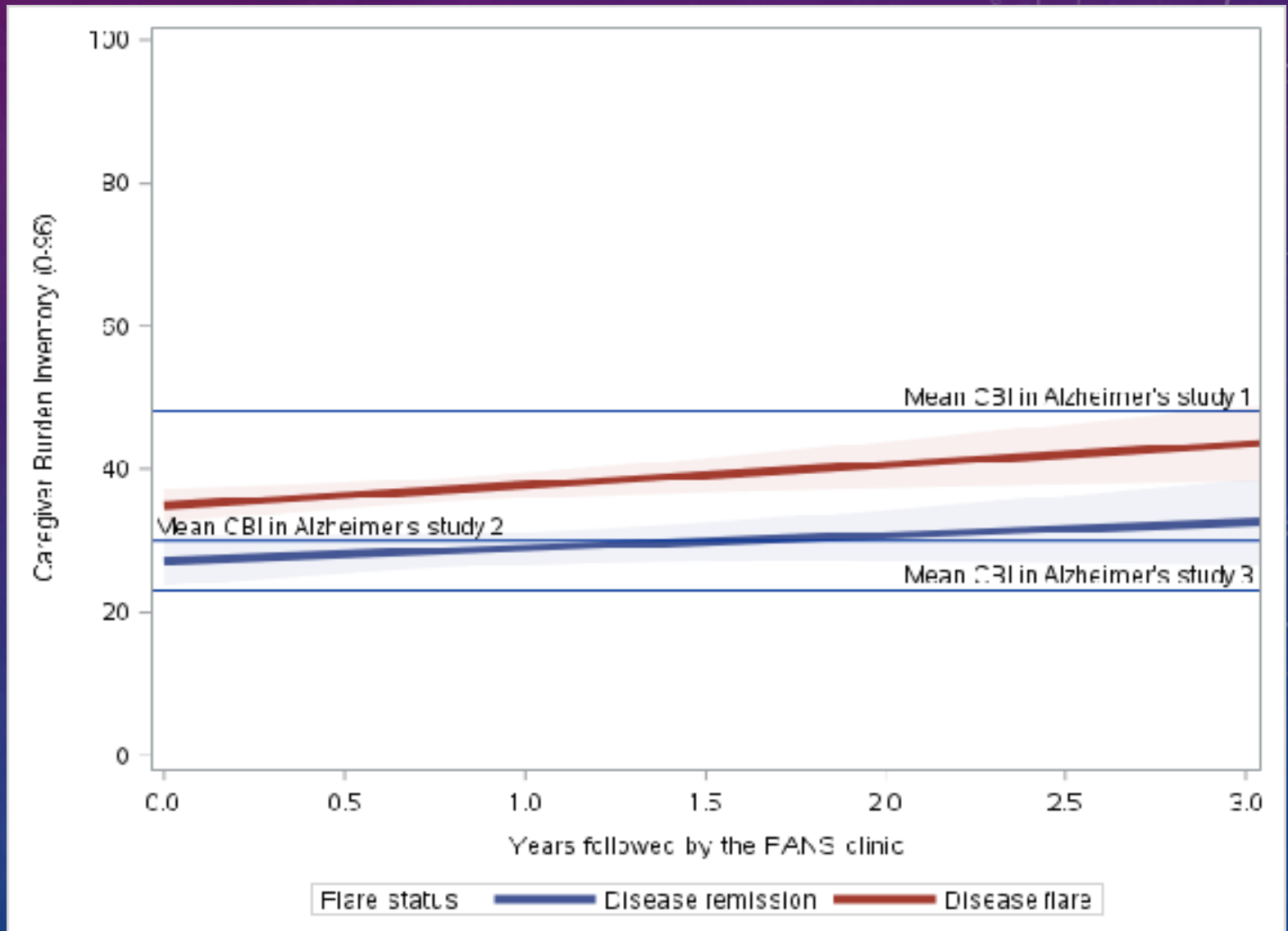
## FINDINGS AND WORKS IN PROGRESS

- Immunology
  - HLA
  - Monocytes
- Treatment Responses
  - NSAIDs
  - Corticosteroids
  - Immune deficiencies
  - Sinus infections
- Symptoms
  - Caregiver Burden
  - Pain, fatigue, exercise intolerance
  - Hallucinations
  - Caregiver Skills Group
  - Cognitive changes

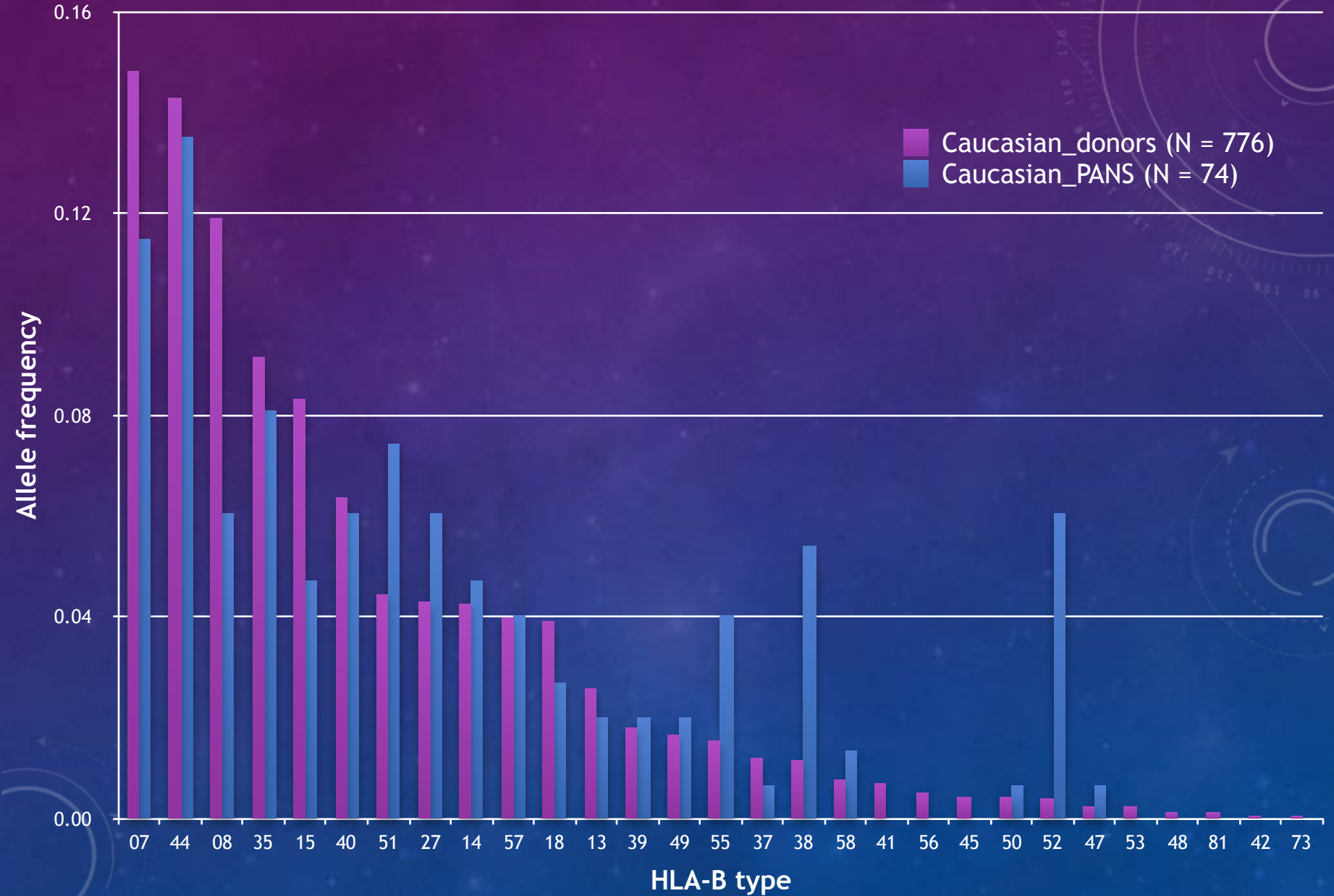
# STANFORD PANS PROGRAM FINDINGS AND WORKS IN PROGRESS

- Immunology
  - HLA
  - Monocytes
  - GAS toxin causing TH17 skew
  - Vasculitis markers
- 
- Treatment Responses
  - NSAIDs
  - IVIG
  - Corticosteroids
  - Rituximab/Mycophenylate/  
Methotrexate
  - Immune deficiencies
  - Sinus infections
- Symptoms
  - Hallucinations
  - Pain, fatigue, exercise intolerance
  - Caregiver Burden
  - Caregiver Skills Group
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# CAREGIVER BURDEN LIKE ALZHEIMERS' FAMILIES

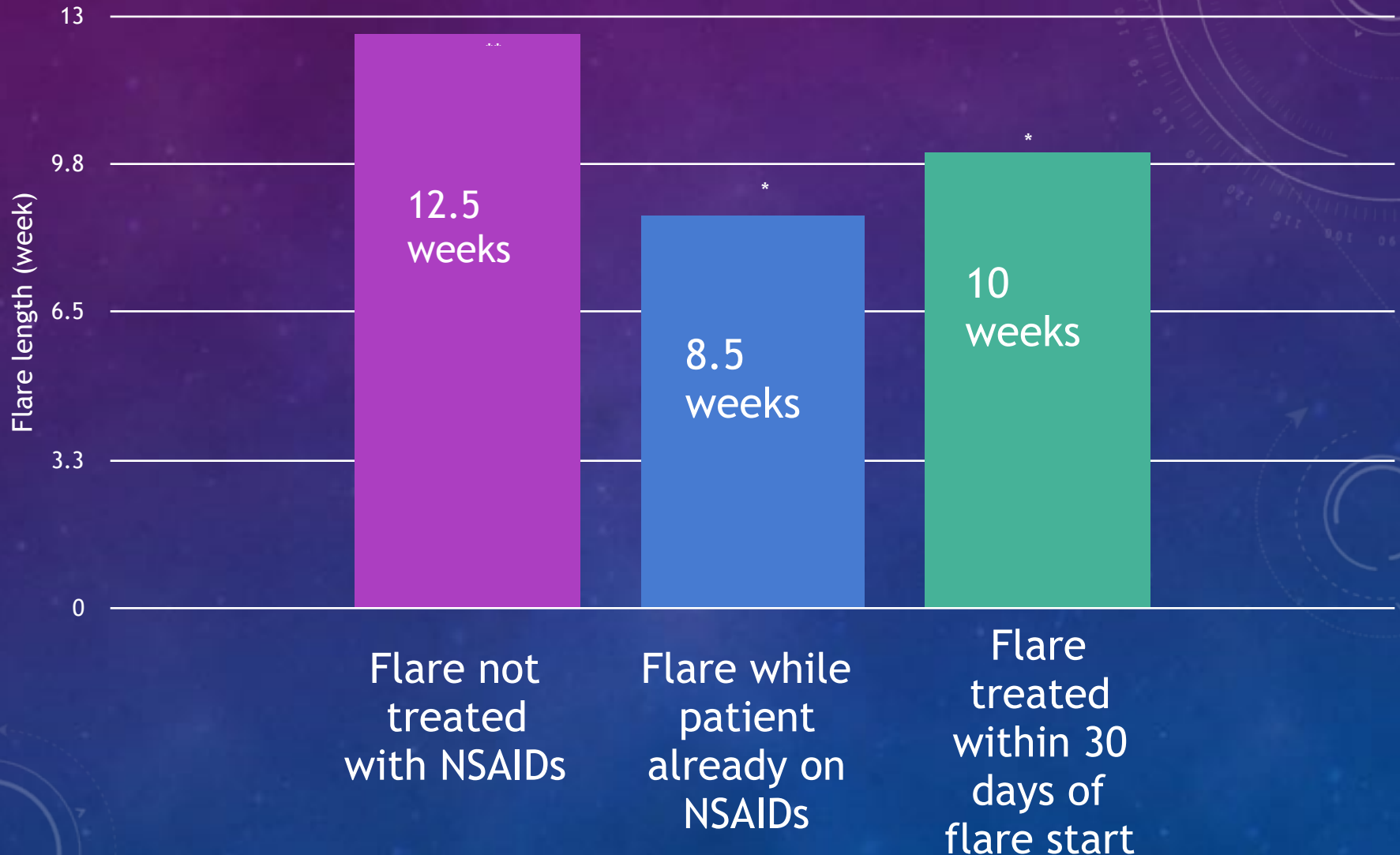


# HLA-B frequencies in caucasian controls and caucasian PANS cases

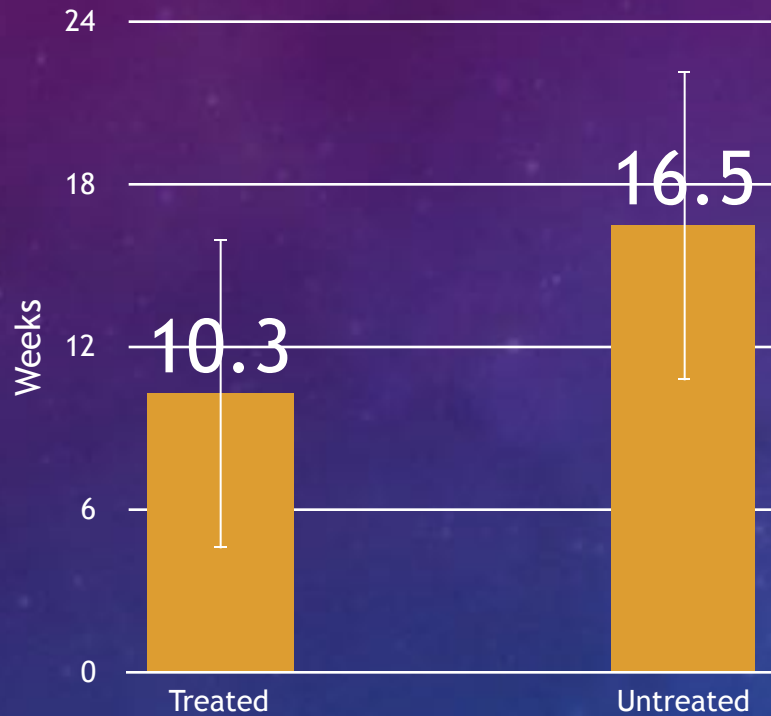




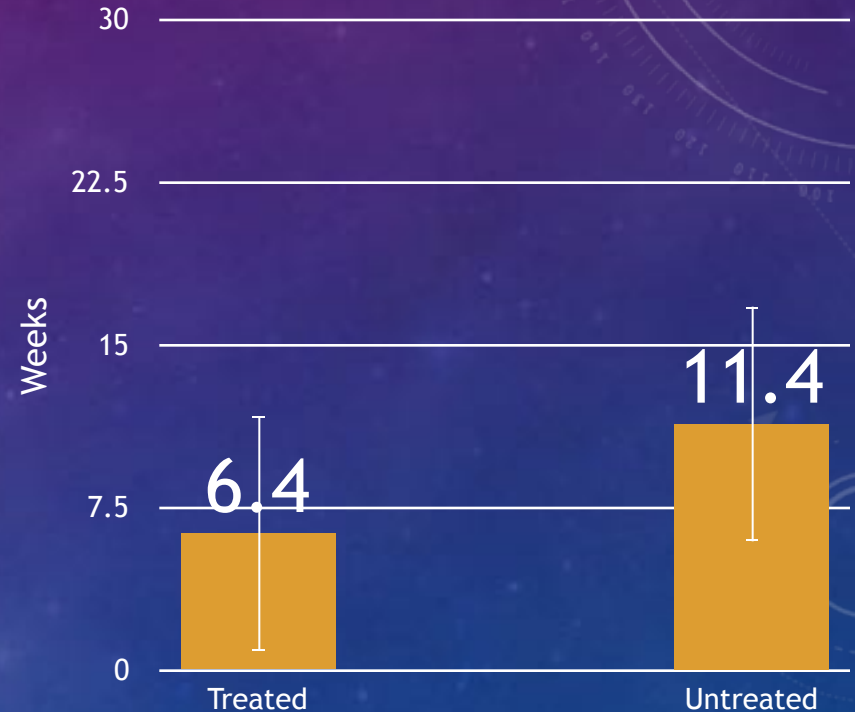
# Effect of early and prophylactic NSAIDs on flare duration



# EFFECT OF CORTICOSTEROIDS ON WEEKS IN FLARE



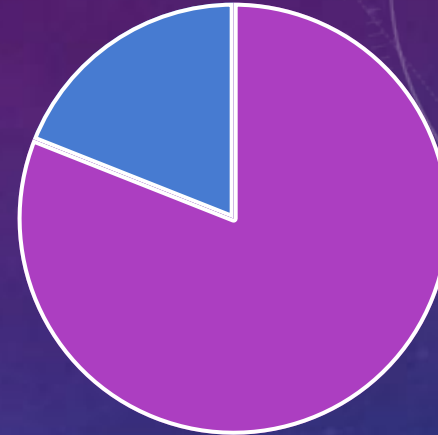
Single episode of PANS or relapsing/remitting PANS



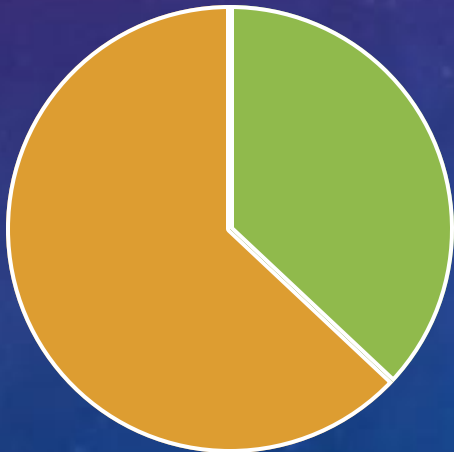
Duration of the initial presentation (i.e., first PANS flare) of PANS

# SYMPTOM PREVALENCE FINDINGS

PAIN, FATIGUE OR EXERCISE INTOLERANCE:  
81%



SENSORY  
DISTURBANCE/  
HALLUCINATIONS 37%



HALLUCINATIONS  
n= 153

