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

Obsessions
Compulsions
Anxiety
Hyperactivity
Mood
Rage
Cognitive changes
School trouble

Tics
Behavior Problems
Evaluation and Treatment

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

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

- **2012**: Stanford PANS Program
- **2013**: PANS Consensus Diagnostic Guidelines
- **1998-2016**: Animal models support roles of GAS Antibodies T-cells
- **2000, 2015**: MRI PET Studies
- **1995-2016**: IVIG TPE NSAID Steroid Series
- **2017**: Double-blind PANS Azithromycin Trial
- **2017**: PANS Consensus Treatment Guidelines
- **Currently here…**: HLA Population Studies Immune cell characterization
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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
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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
  - Cognitive changes
CAREGIVER BURDEN LIKE ALZHEIMERS’ FAMILIES

Project status: Manuscript currently under review.
HLA-B frequencies in caucasian controls and caucasian PANS cases

Caucasian_donors (N = 776)
Caucasian_PANS (N = 74)
Effect of early and prophylactic NSAIDs on flare duration

- Flare not treated with NSAIDs: 12.5 weeks
- Flare while patient already on NSAIDs: 8.5 weeks
- Flare treated within 30 days of flare start: 10 weeks
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

- None: 68
- Visual: 90
- Auditory: 45
- Other: 23

None