

# The value of the whole:

## Psychosocial considerations for pediatric neuroimmune disease

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2022 RNDS

10/07/2022



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**2022RNDS**  
connect. care. cure.™

# Disclosures

No disclosures to report



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# Objectives

1. Identify mental health needs in the neuroimmune population
2. Demonstrate the high needs in a local clinic population
3. Describe three important steps caregivers and treatment providers can do to meet these needs



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# Audience participation please!

Enter words that you connect  
to neuroimmune disease

Use the QR code

OR

Text 61850 and your word to  
22333



Note: Please keep words child friendly!

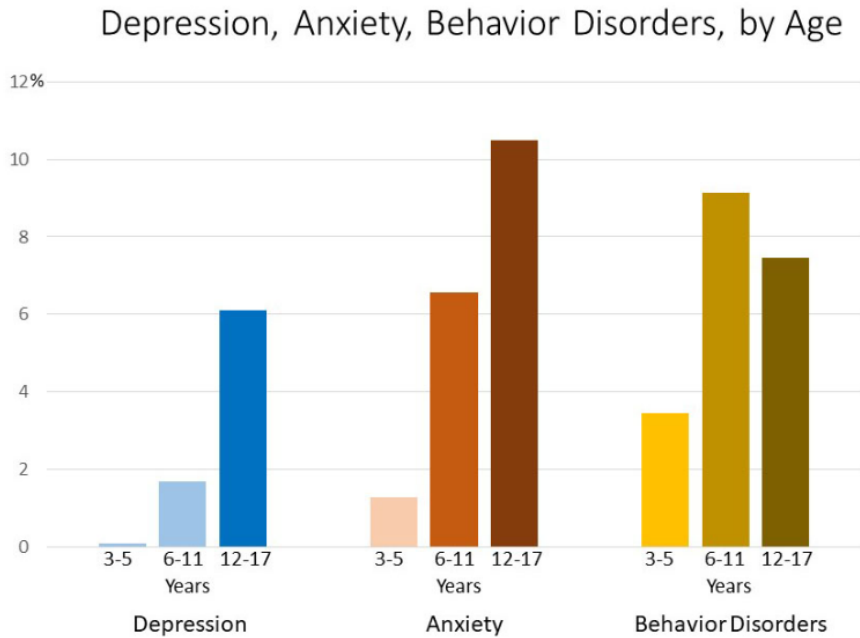


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# Pediatric Mental Health Facts



Center for Disease Control, 2022

**50%** of all lifetime mental illnesses start by age 14\*

\*National Institute of Mental Health

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The Movement for Children's Mental Health

**1 in 5 children** has a significantly impairing mental disorder; yet less than half get the treatment they need\*

\*National Institute of Mental Health

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# Background

- Impact of a demyelinating disorder is widespread
  - Anxiety, ADHD, mood symptoms are most common diagnoses
  - High overlap of cognitive and psychiatric disorders
  - Fatigue (up to 75% in MS studies)
  - Lower quality of life ratings – especially for relapsing disease

Duncan et al., *Dev Med Child Neurol*, 2020

# NCH Neuroimmune (NI) Clinic



- Started in 2019
- Patient population: rare autoimmune or inflammatory disorders of the central nervous system (CNS)



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# NCH Neuroimmune (NI) Clinic

- Weekly multidisciplinary clinic
- Allows for focused evaluations within one setting
- Annual neurocognitive screening
- Annual psychosocial screening





# NI Clinic Psychosocial Screening

- RedCap questionnaire
- Completed annually
- Families and patients can complete before clinic or during clinic with iPad
- Feedback shared with family during clinic appointment



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# NI Clinic Psychosocial Screening

Measure	Informant	Domain	Age Range (years)
PROMIS Fatigue	Child	Fatigue	8-17+
SCARED	Child	Anxiety	8-18
CES-DC	Child	Depression	6-17
PHQ-9	Teen/Young Adult	Depression	12+
PROMIS Fatigue	Parent	Fatigue	5-17+
Vanderbilt	Parent	Attention, behaviors	6-12
LEAF	Parent	Learning, executive and attention functioning	6-18+



# Psychosocial Screening Results

- Questionnaires completed 2020-2022
- 54 adolescents + family caregiver
- 57% female
- 6-19 years (average age = 13.20 years)
- Diagnoses: ADEM, Optic Neuritis, Multiple Sclerosis, Transverse Myelitis, encephalitis (other)



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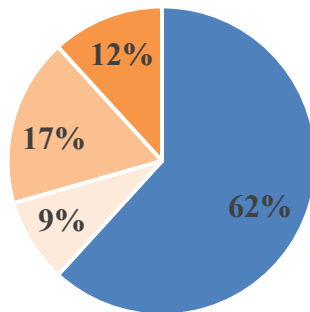


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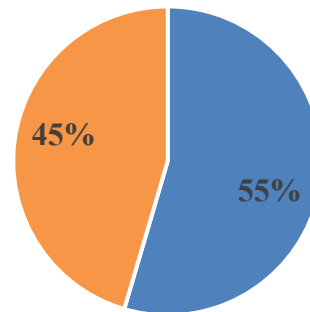
# Psychosocial Screening Results

## Overall **Child/Adolescent** ratings (all diagnoses)

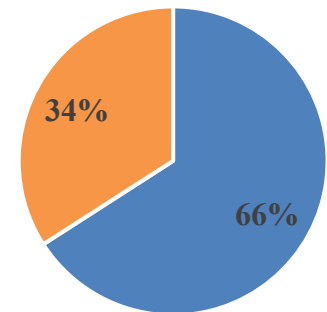
Fatigue (PROMIS)



Depression (CES-DC)



Anxiety (SCARED)



■ Normal ■ Mild ■ Moderate ■ Severe

■ Not Elevated ■ Elevated

■ Not Elevated ■ Elevated

Leever et al., unpublished data



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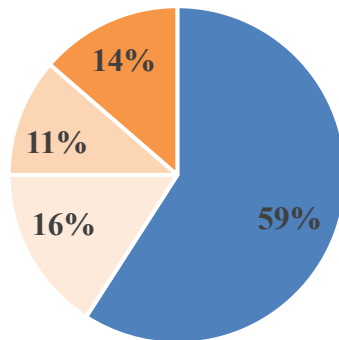


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# Psychosocial Screening Results

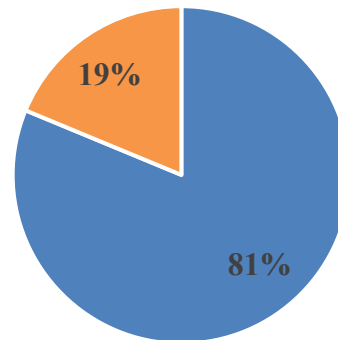
## Overall **Parent** ratings (all diagnoses)

Fatigue (PROMIS)



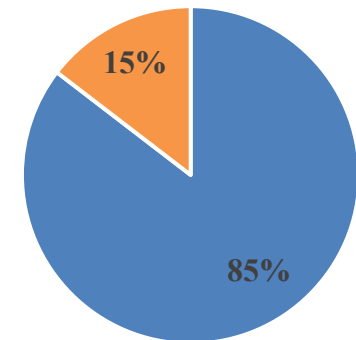
■ Normal ■ Mild ■ Moderate ■ Severe

Inattentive (Vanderbilt)



■ Not Elevated ■ Elevated

Anxiety/Depression (Vanderbilt)



■ Not Elevated ■ Elevated

Leever et al., unpublished data



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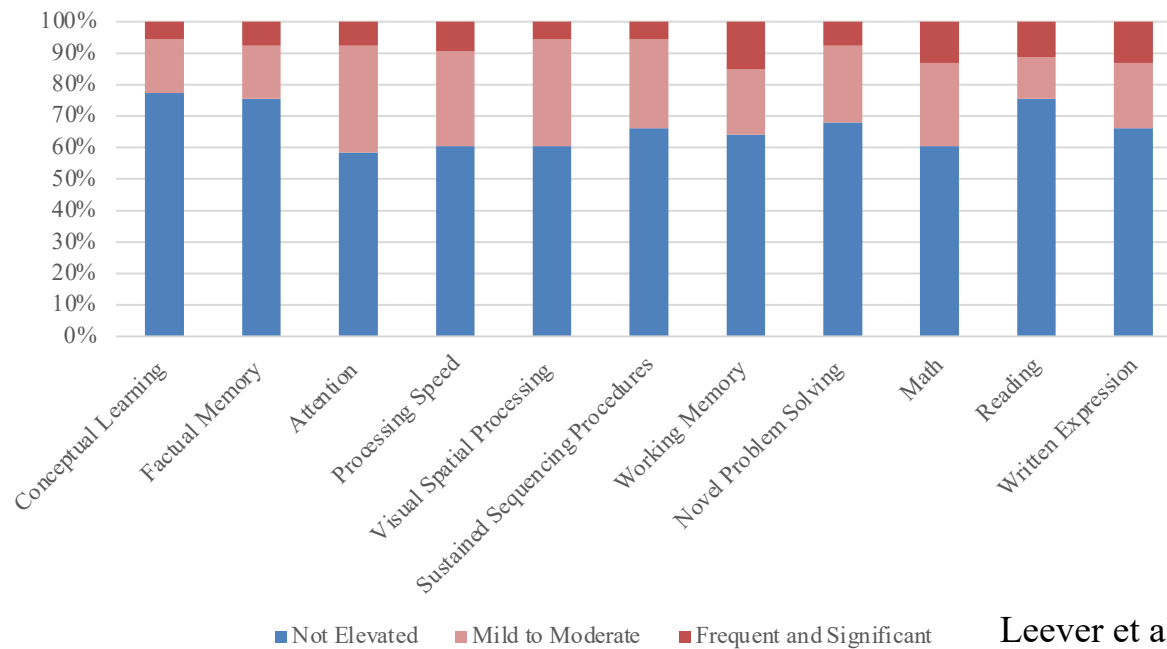


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# Psychosocial Screening Results

## Overall Parent ratings (all diagnoses)

### Learning, Executive, Attention Functioning (LEAF)



Leever et al., unpublished data



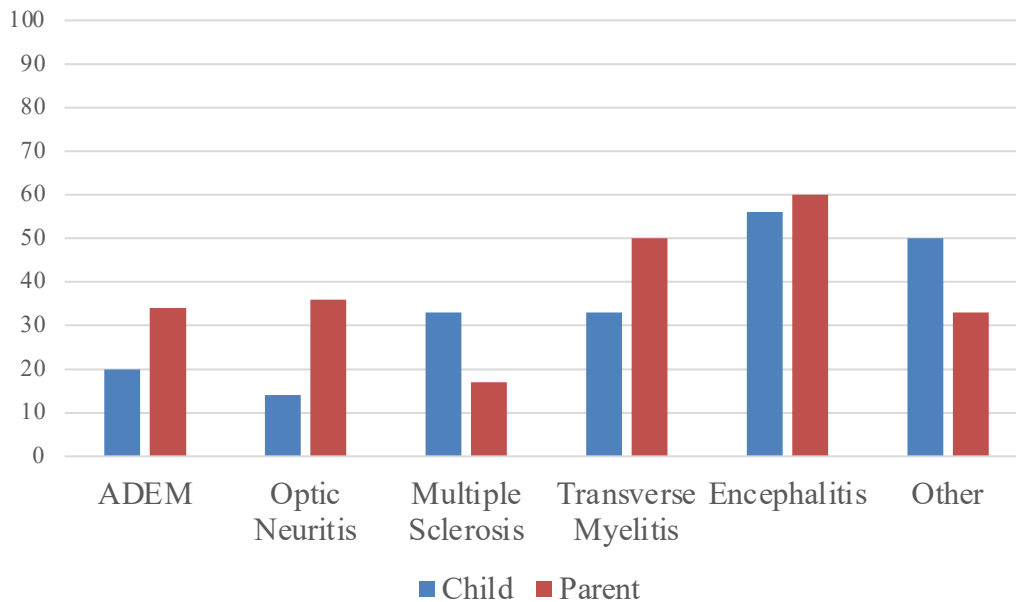
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# Psychosocial Screening Results

Fatigue Ratings by Medical Diagnosis



- Expected high levels seen with Transverse Myelitis, ADEM
- High levels also in Optic Neuritis and encephalitis

Leever et al., unpublished data



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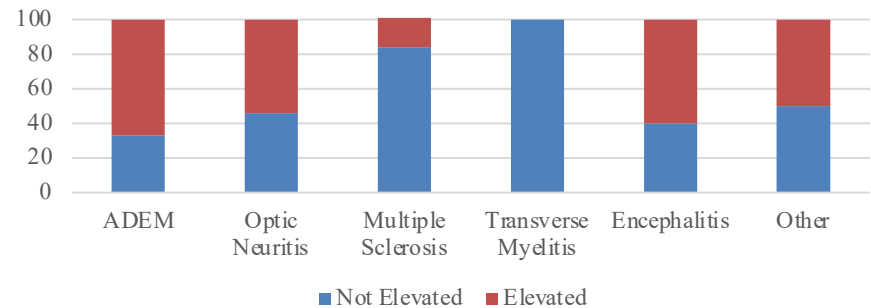


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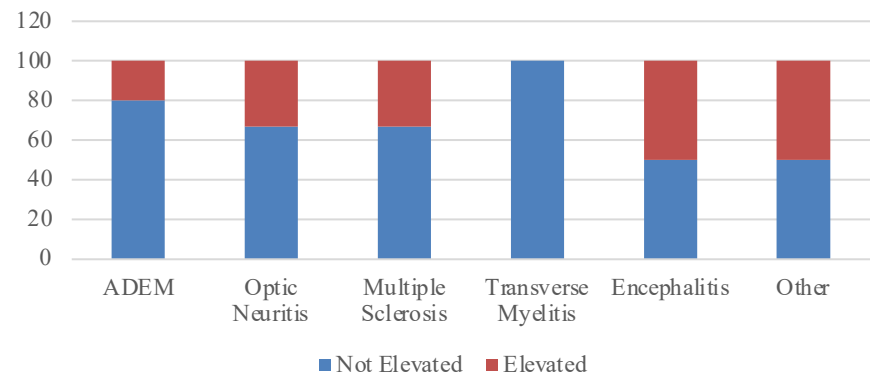
# Psychosocial Screening Results

- Very high self-reported rates of depression across ADEM, Optic Neuritis, encephalitis (> 50%)
- High rates of anxiety in Optic Neuritis, MS, and encephalitis
- Consider the impact of chronic medical diagnosis on mental health

Depression ratings by medical diagnosis



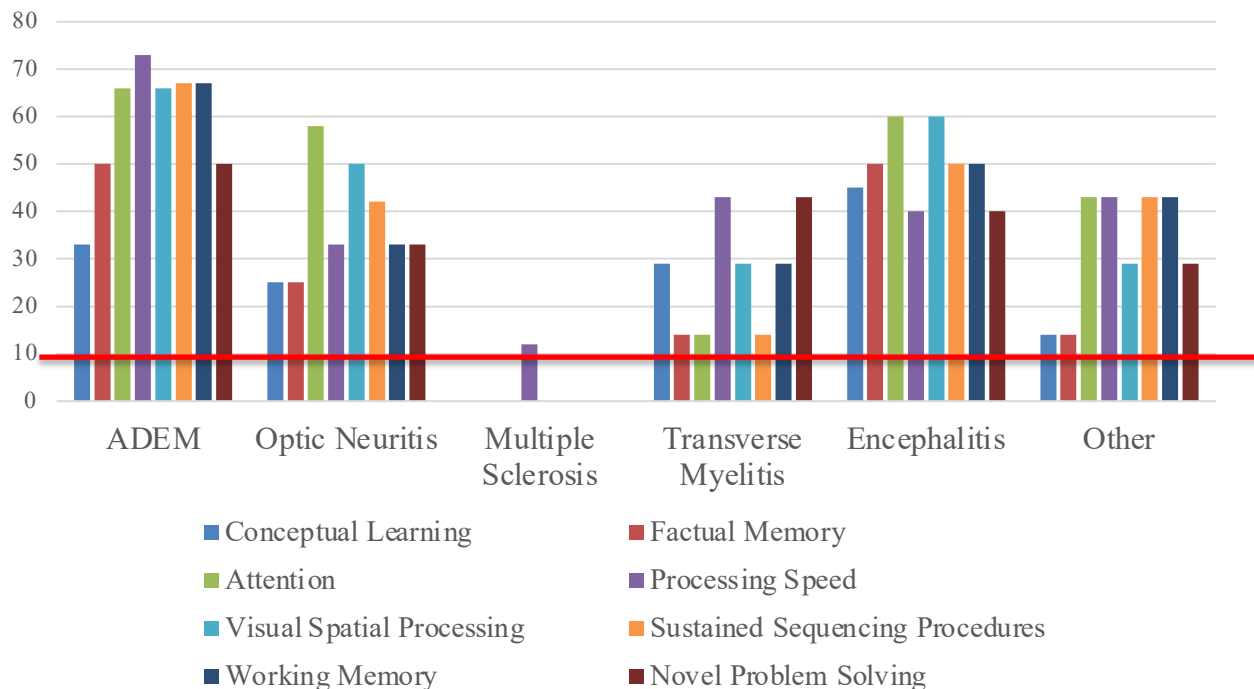
Anxiety ratings by medical diagnosis





# Psychosocial Screening Results

## Executive, and Attention Functioning by Medical Diagnosis



Leever et al., unpublished data



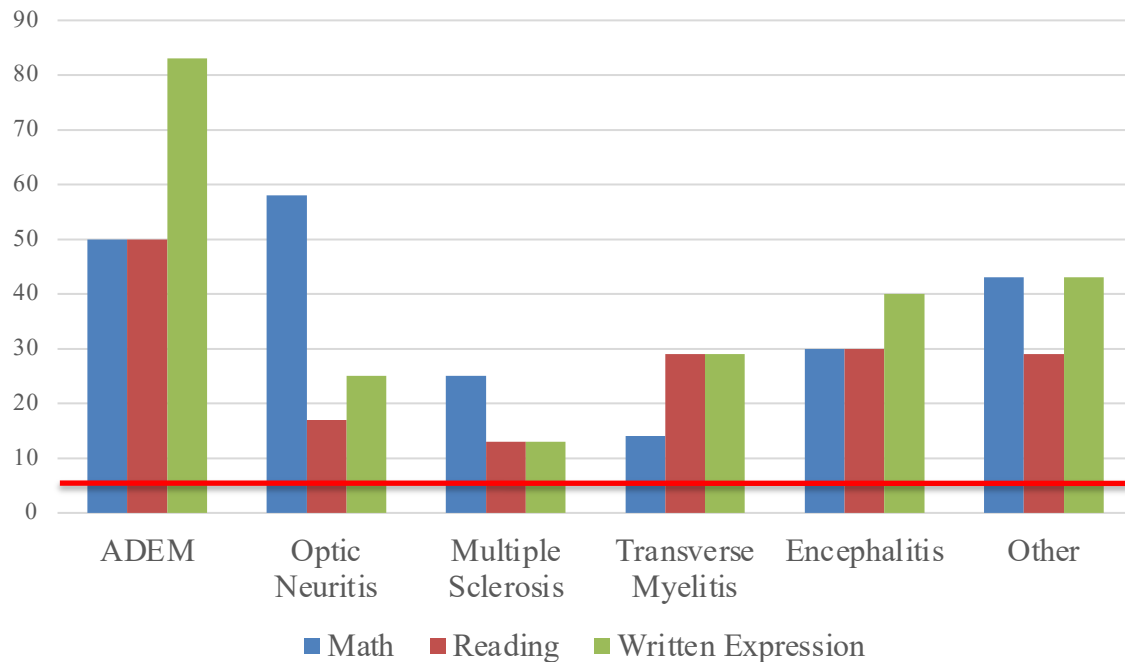
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# Psychosocial Screening Results

Learning Concerns By Medical Diagnosis



- High rates of learning concerns across diagnoses
- ~2% learning disability diagnoses in the general population

Leever et al., unpublished data



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# Psychosocial Screening Results

Of the 54 individuals screened:

- 39% have been linked with psychiatry
- 69% have been connected with Psychology/Behavioral Health
- 52% have completed a neuropsychological evaluation



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# Key Takeaways

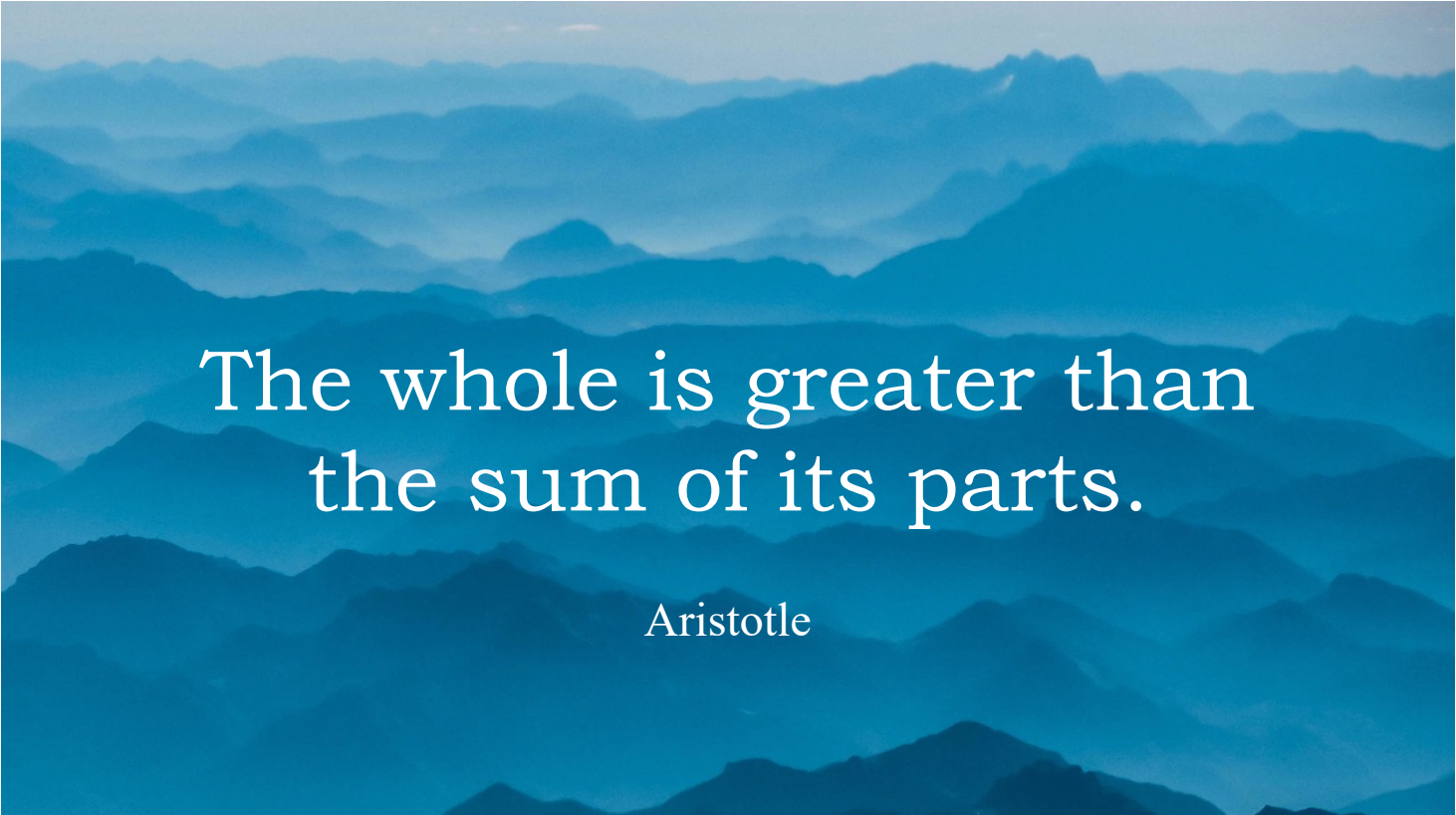
- **Anxiety and depression** co-exist with medical diagnoses
- High rate of **learning concerns**
- **High utilization rates** for psychology/psychiatry services
- Important to consider needs beyond medical management
- Need to **consider mental health needs** in this population



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The whole is greater than  
the sum of its parts.

Aristotle



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# How can you support

1. Regular **ongoing mental health screening** is recommended
2. Know the **early signs of mental health** concerns
3. Recognize when someone may be having **difficulty with learning**
4. Seek out **behavioral health or educational supports** when you see signs of struggle



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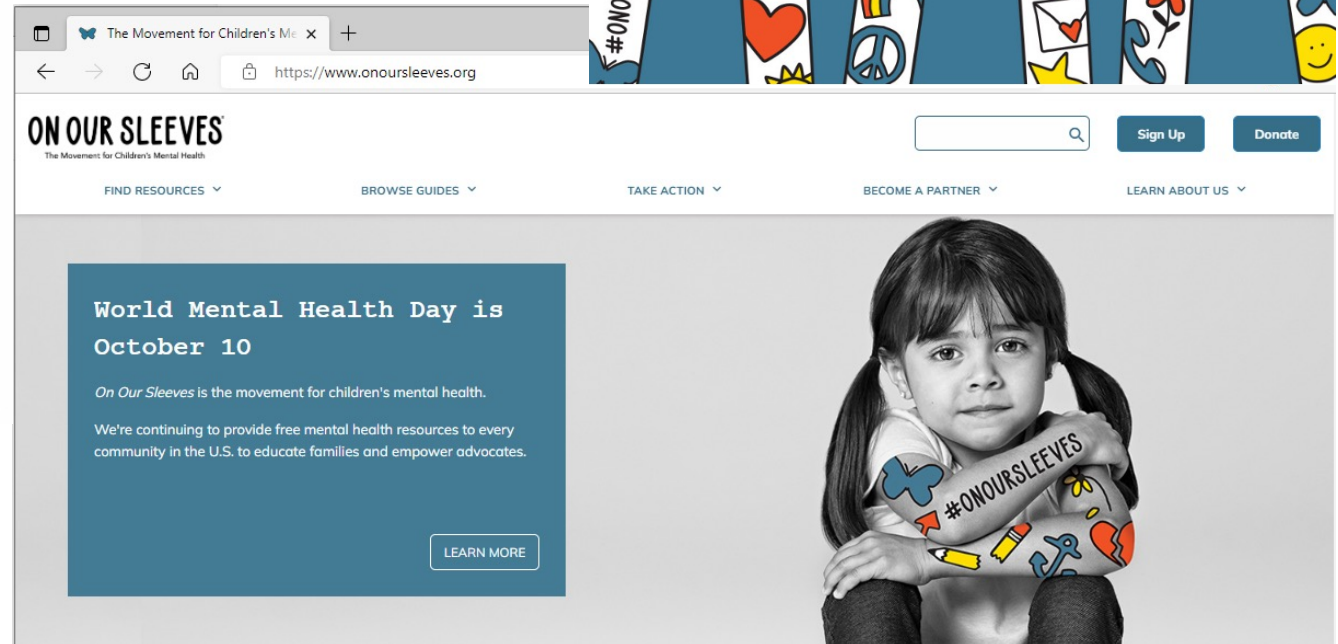


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# Family and Clinician Resources

## On Our Sleeves

[www.onoursleeves.org](http://www.onoursleeves.org)



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# Special thanks

Neuroimmune Dream Team

Psychosocial team extraordinaire!

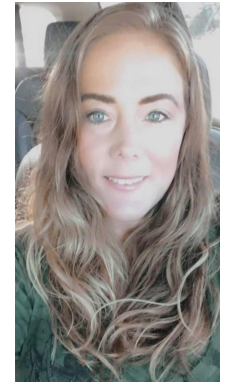
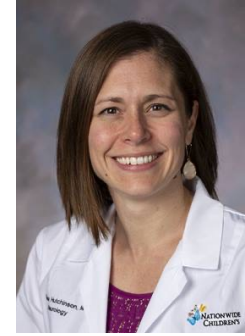
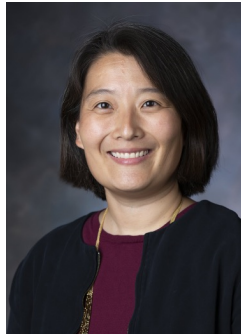
Alana Goldstein-Leever, PsyD  
and Karah Harvey, M.D.

Our patients and families





# NCH Neuroimmune Team

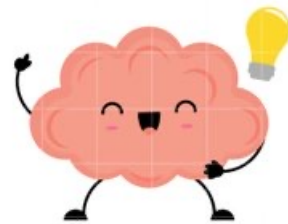


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# Questions?



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