



# **Functional Changes and Pain with Aging and Cerebral Palsy:** *Research findings with Recommendations for consumers*

Mary Gannotti, PT, PhD

Edward Hurvitz, MD

Jodi Kreschmer, MSW

Shannen Bolde, MPH

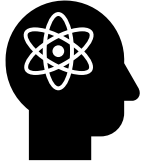
March 25, 2024



Cerebral  
Palsy  
Research  
Network



# Objectives



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Identify

the reasons why adults with cerebral palsy may experience functional changes or pain with aging.

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Describe

describe how common these changes are among other adults with cerebral palsy

---

Identify

identify ways to reduce the impact of pain and functional decline

---

Remember

how to access the Cerebral Palsy Research Network's Adult Surveys on Function and Pain

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Participate in discussions or research on [CP](#).

Join

Log in

# Schedule of Speakers

- **Questions Adults with CP Have (5 min)**
  - *Jodi Kreschmer, MSW/Shannen Bolde, MPH*
- **Why Functional Decline and Pain? (15 min)**
  - *Dr. Hurvitz*
- **Adult Surveys on Function & Pain (10 min)**
  - *Mary Gannotti, PT, PhD*
- **Pain types and treatments (10 min)**
  - *Mary Gannotti, PT, PhD*
- **Why join MyCP? (5 min)**
  - *Jodi Kreschmer, MSW/Shannen Bolde, MPH*
- **Discussion (10 min)**

# What Questions Do Adults with Cerebral Palsy Have?

*Jodi Kreschmer, MSW*



How might my abilities change as I age?

Where is my pain from?

Does it matter what type it is?

How can I manage it?



# How might my abilities change as I age?

**Why Functional Decline and Pain?**

**Dr Hurvitz**

# Lifespan with CP—Good News!

- High Functioning (GMFCS I and II)
  - Excellent survival—98.2%
  - Regular lifespan
- Survival for “Less Mobile” (GMFCS IV-V) is on the rise!
  - Increasing average life span
- Over 500,000 adults with CP in US



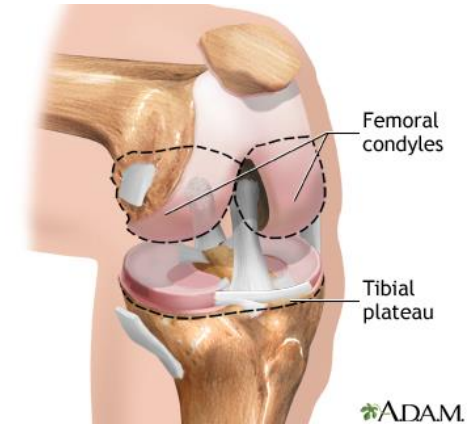
# Development in Cerebral Palsy



BONES



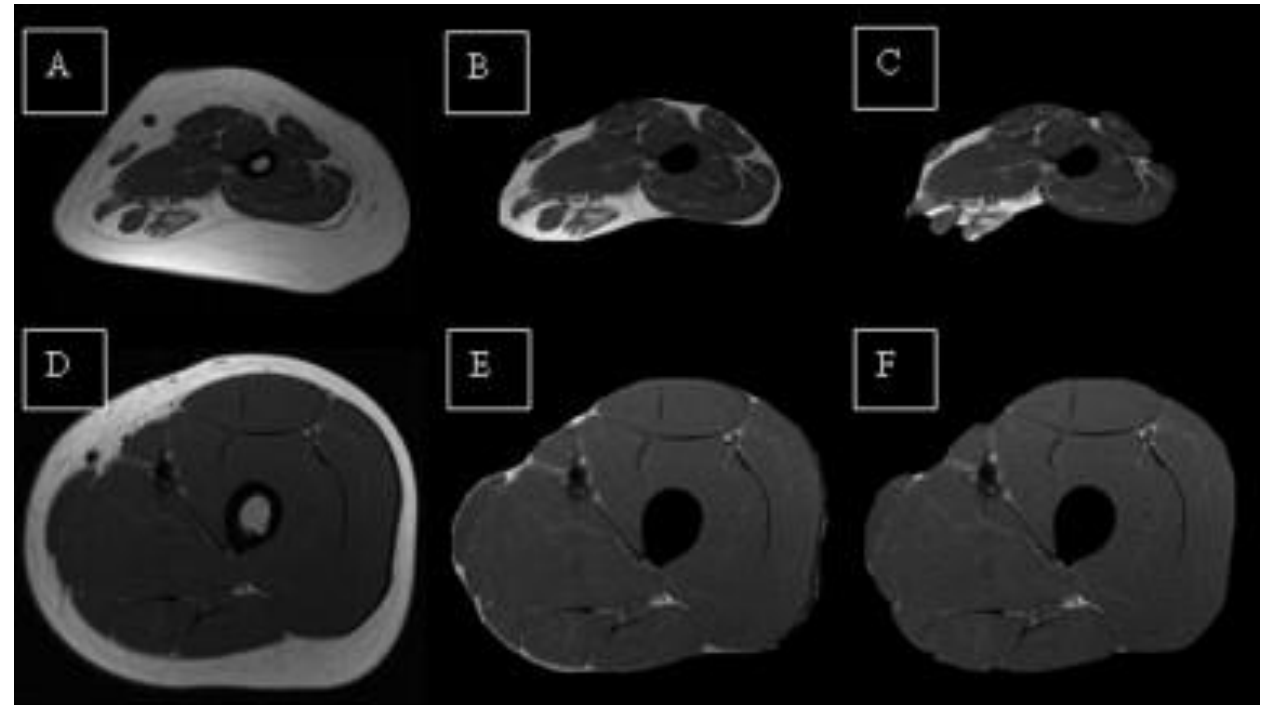
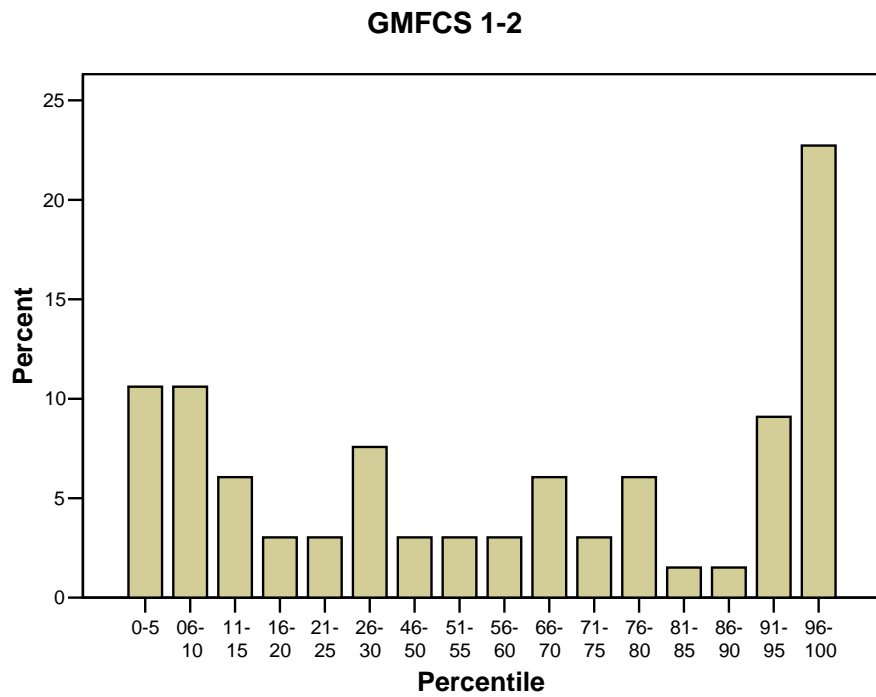
MUSCLES



Joints

# Low fitness and Obesity

Figure 1. Distribution of Percentiles for





# Painful Joints



HIP DISLOCATION



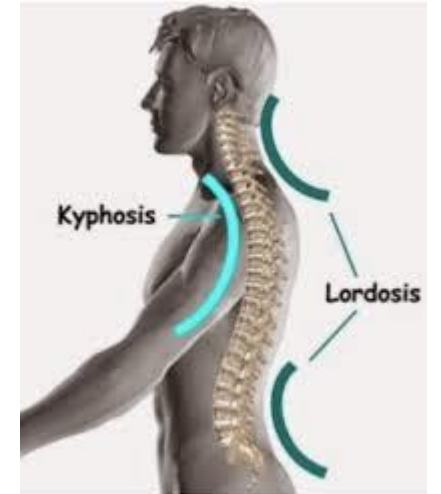
ASSISTIVE DEVICES



CONTRACTURES

# Walking affected

- Tight hamstrings leads to strain on back—Lordosis
- Spasticity and contracture change walking pattern



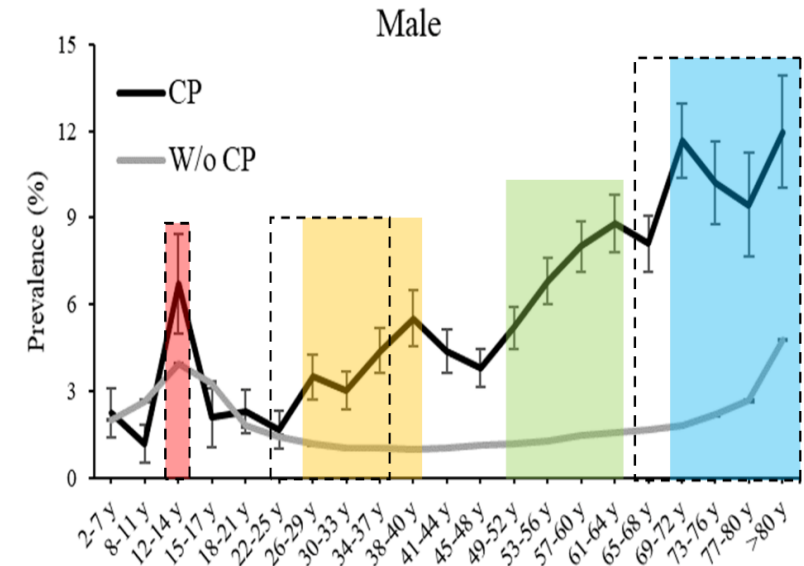
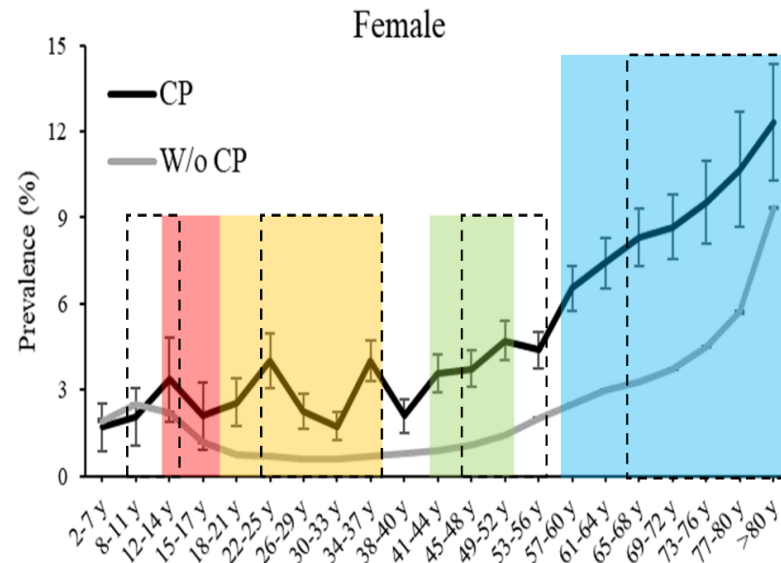
# Spasticity



shutterstock.com · 242098309

- Spasticity can increase
  - More changes in gait
  - More stress on joints
- Neurologic causes
  - Spinal Stenosis
  - Stroke
- Lack of stretching
- Lack of treatment

# Falls and Fractures



Fracture rates for females higher through the lifespan

Fracture rates for males MUCH higher

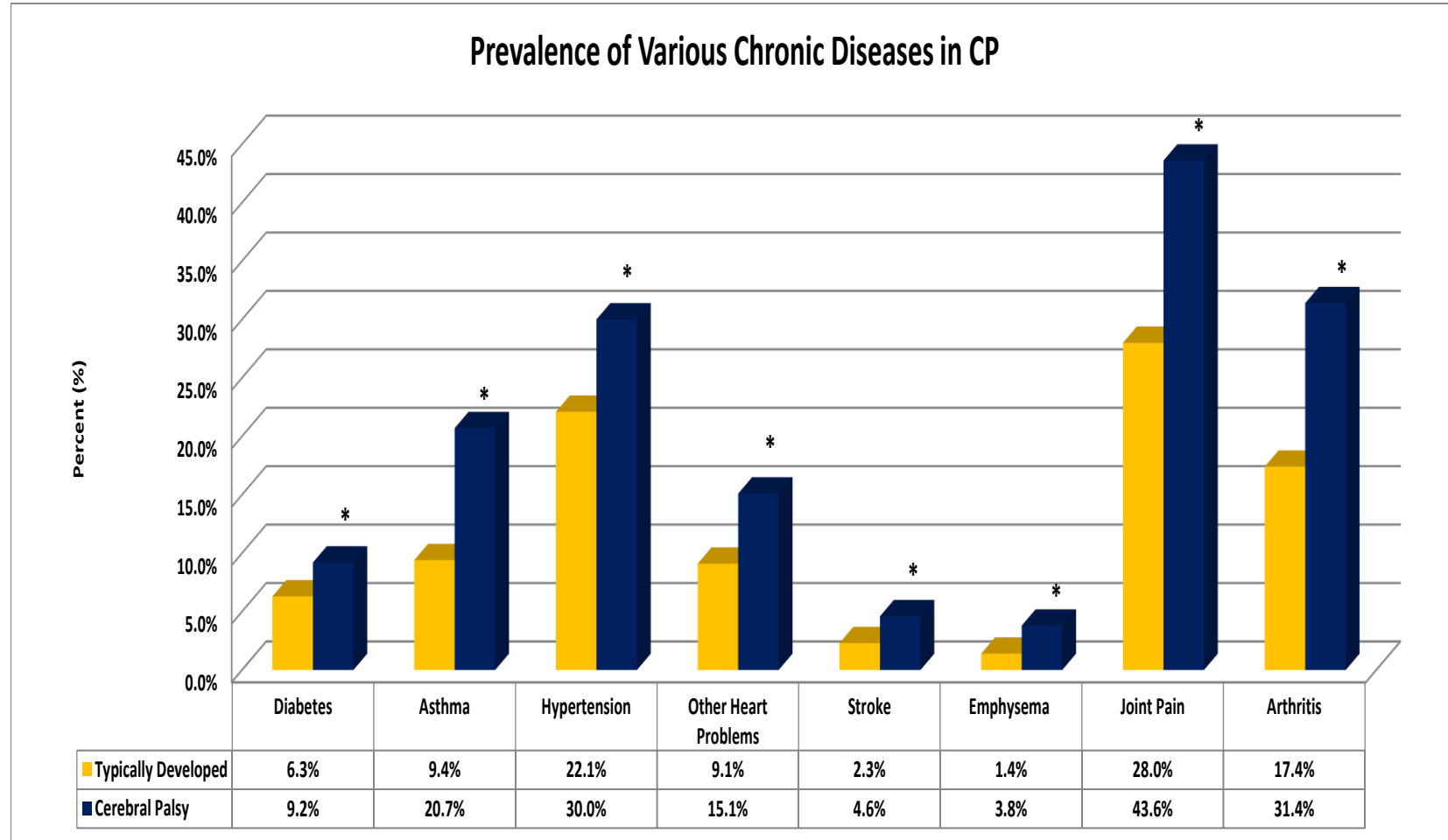
# Nerve impingement

- Spinal stenosis
  - Back
  - Neck
- Nerve caught due to contractures
- Carpal tunnel from walker use



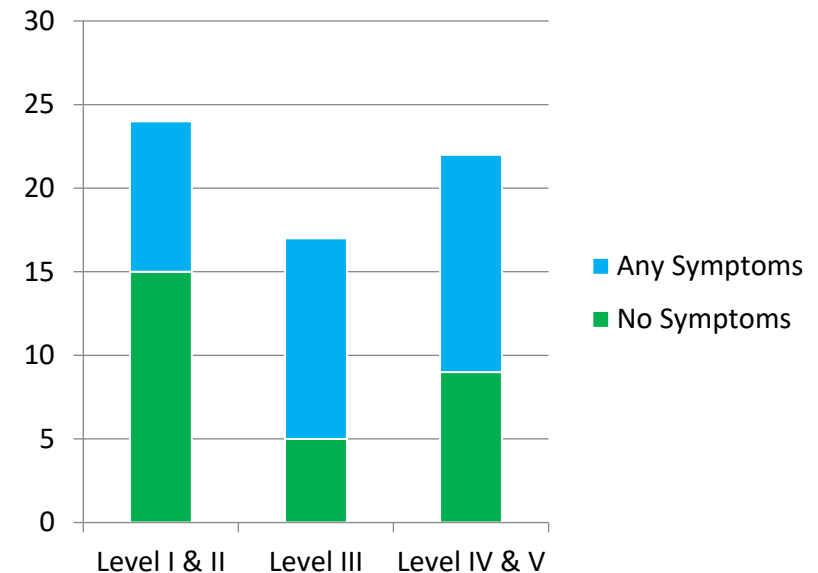
# Chronic disease

- Heart disease
- Kidney disease
- Respiratory  
(breathing/lung)  
disease
- Inflammation
  - Obesity



# Bowel Problems

- Constipation
  - 1/3 of a community population
  - 52% had some symptoms
- Irritable bowel syndrome
- Nutrition
- Lower levels of movement



# Fatigue, Sleep and Depression



*Contribute to  
pain...*



*Made worse  
by pain!*



# Set up for pain from the early years



# Main predictor of Quality of Life

- Pain is part of life in CP
- Studies show main difference in QOL due to pain
- Pain treatment complex in CP
- Greater understanding will help develop better treatment





# How might my abilities change as I age?

**Adult Surveys on Function & Pain**

**Mary Gannotti, PT, PhD**


# Community Registry Goals


- Collect information about what people are experiencing, what works, and what does not.
- Look for patterns for prevention and treatment
- Lifespan clinical registry → longitudinal data
  - But this takes time!
  - And may be biased towards those receiving specialty care at tertiary centers
- Patient-reported outcomes (PRO) → more expedient data collection
  - Experiences of adults in broader community




# Internet Presence for Broad Community

Engaging the Cerebral Palsy Community in Research That Matters

Donate Blog Log In 

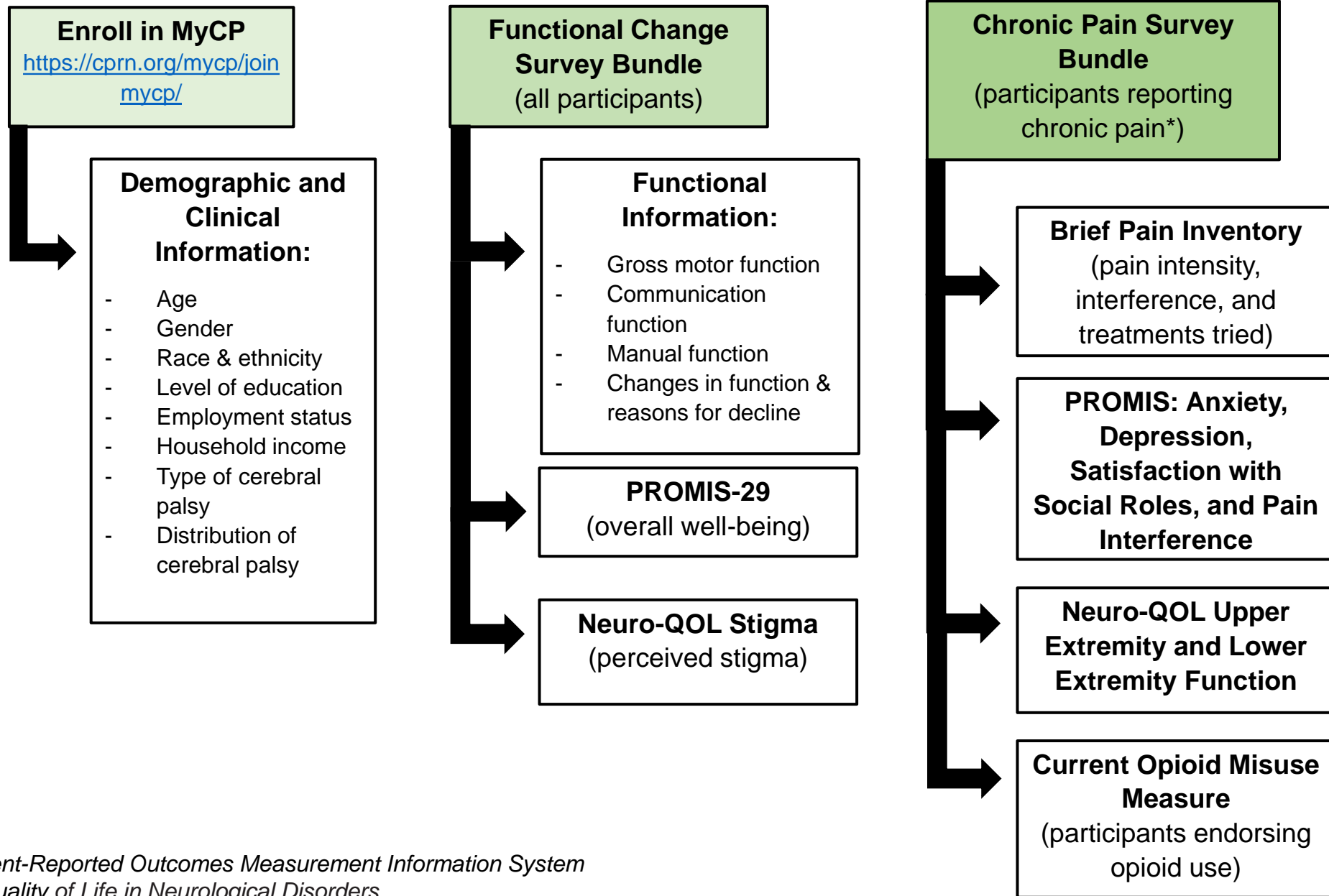
 Cerebral Palsy Research Network

[Cerebral Palsy](#) [Adults with Cerebral Palsy](#) [Cerebral Palsy Research](#) [Clinicians & Researchers](#) [About Us](#)



CP Research Network focuses on optimizing the lifelong health and wellness of people with cerebral palsy and their families through high quality research, education and community programming.

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CP Research Network



*PROMIS – Patient-Reported Outcomes Measurement Information System*

*Neuro-QOL – Quality of Life in Neurological Disorders*

*\*Chronic pain defined as pain persistent for >3 months*





# Recruitment

- Social media posts and blogs
- Organizations that provide resources for adults with CP
- Through centers associated with CPRN
- Webinars with educational content provided to community (and recorded)
  - Includes information about registry

# Functional Classification Scales n =264

## GMFCS

- I: 22%
- II: 46%
- III: 12%
- IV: 12%
- V: 4%

## MACS

- I: 46%
- II: 32%
- III: 11%
- IV: 5%
- V: 2%

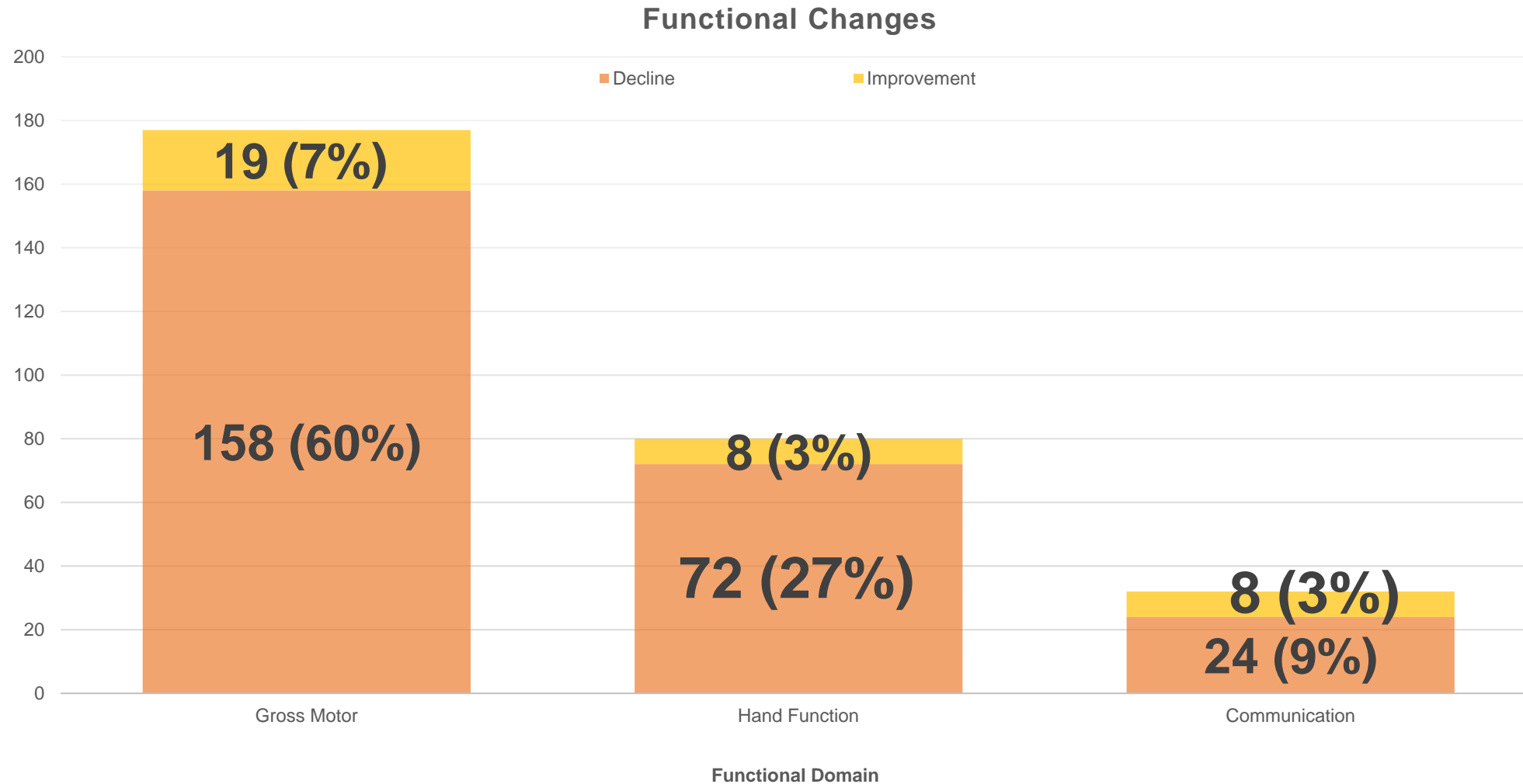
## CFCS

- I: 78%
- II: 17%
- III: 2%
- IV: 2%
- V: 0%



# Results: Functional Change N= 264

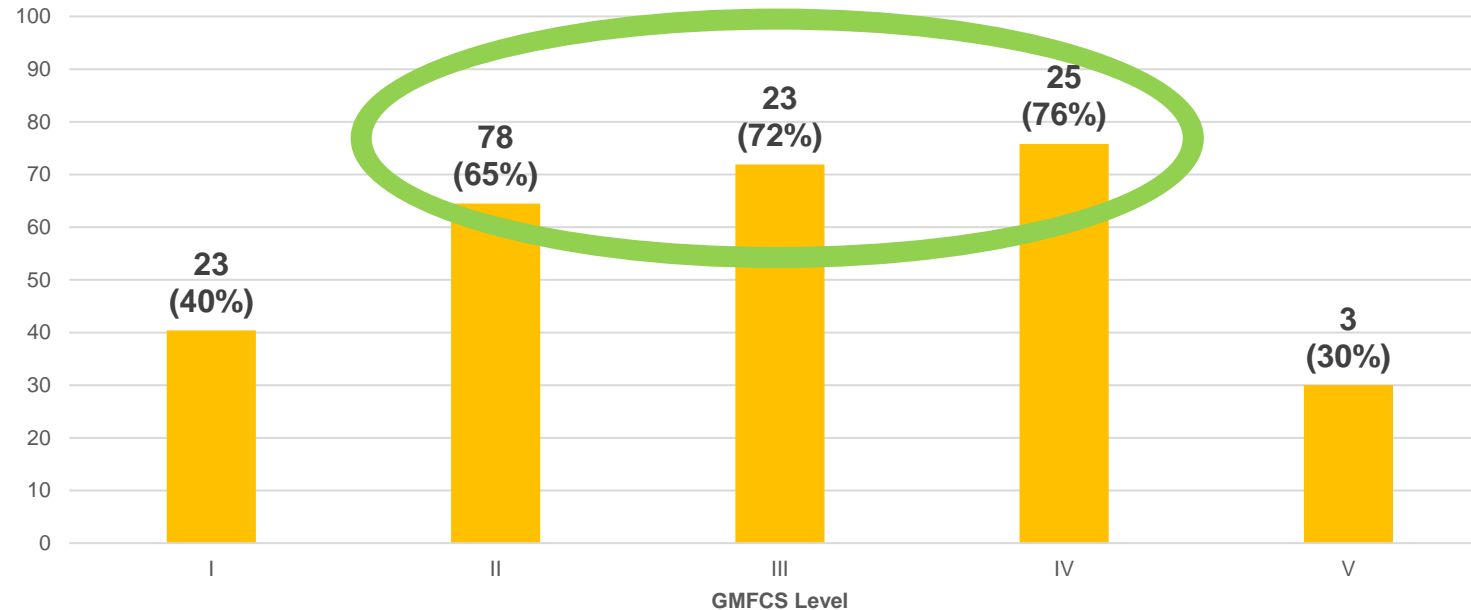
Gannotti et al 2024 Dis Health



Functional changes self-reported by adults with cerebral palsy by functional domain; reported as n (% out of total respondents).

# Results: Functional Change by GMFCS N= 264

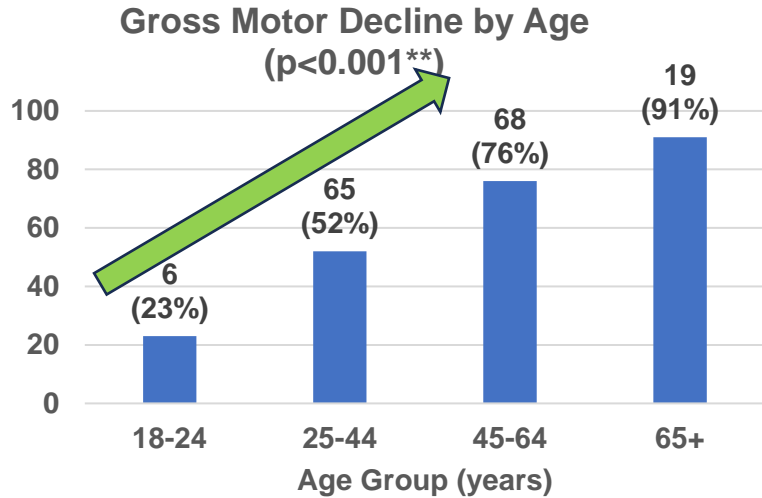
## Gross Motor Decline by GMFCS ( $p < 0.001^*$ )



Gross motor functional decline by GMFCS; reported as n (% within functional level).

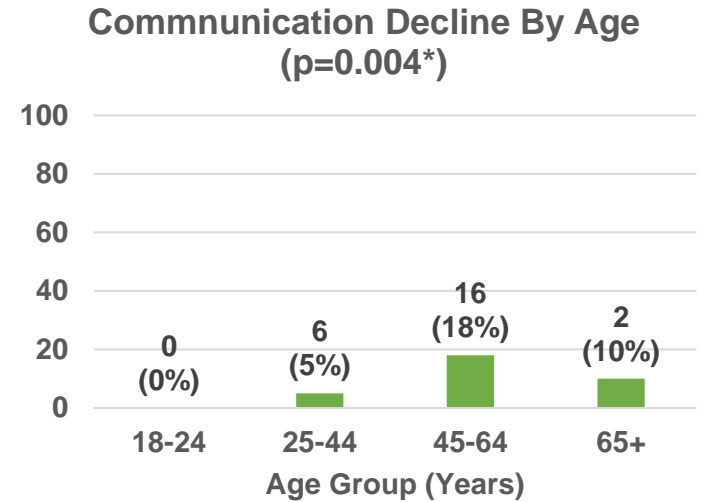
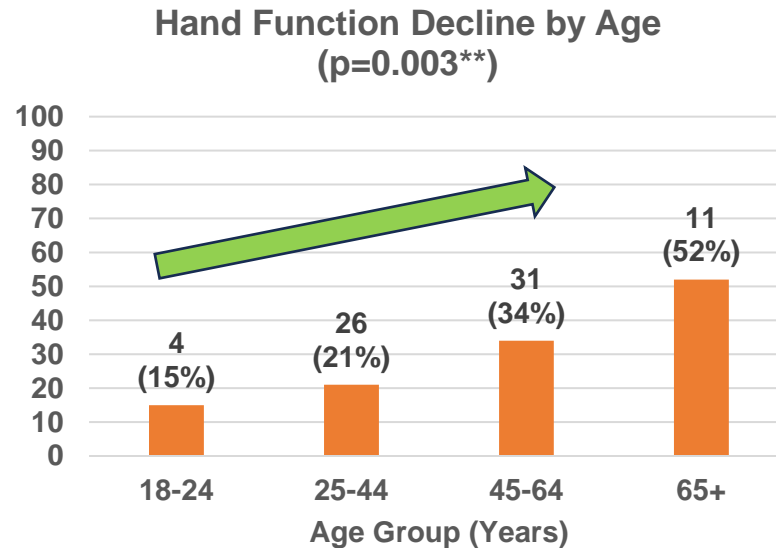
\*Fisher exact

# Results: Functional Change by Age Group N=264



Gross motor functional decline by age group; reported as n (% within age group).

Hand functional decline by age group; reported as n (% within age group).



Communication decline by age group; reported as n (% within age group).

\*Fisher exact  
\*\*Pearson chi-square

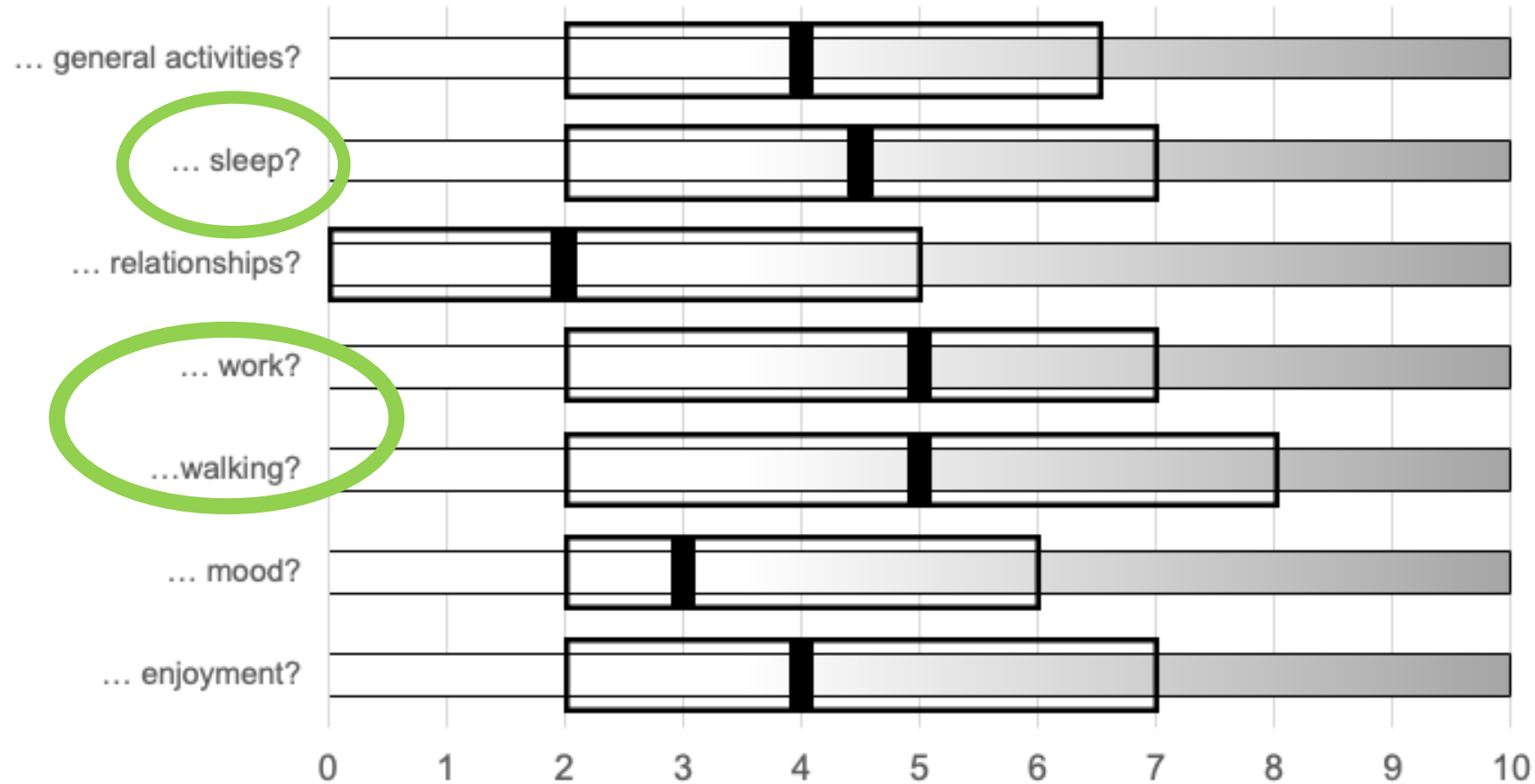
# Results: Reasons for Functional Change

Reasons for Functional Change (N=263)	
Pain	142 (54%)
Fatigue	130 (49%)
Change in strength, increasing weakness	111 (42%)
Change in spasticity/dystonia	103 (39%)
Change in lifestyle, exercise, equipment	64 (24%)
Surgery	39 (15%)
Progressive deformity	33 (13%)
Medical condition other than CP	24 (9%)
Therapy or other treatments	18 (7%)

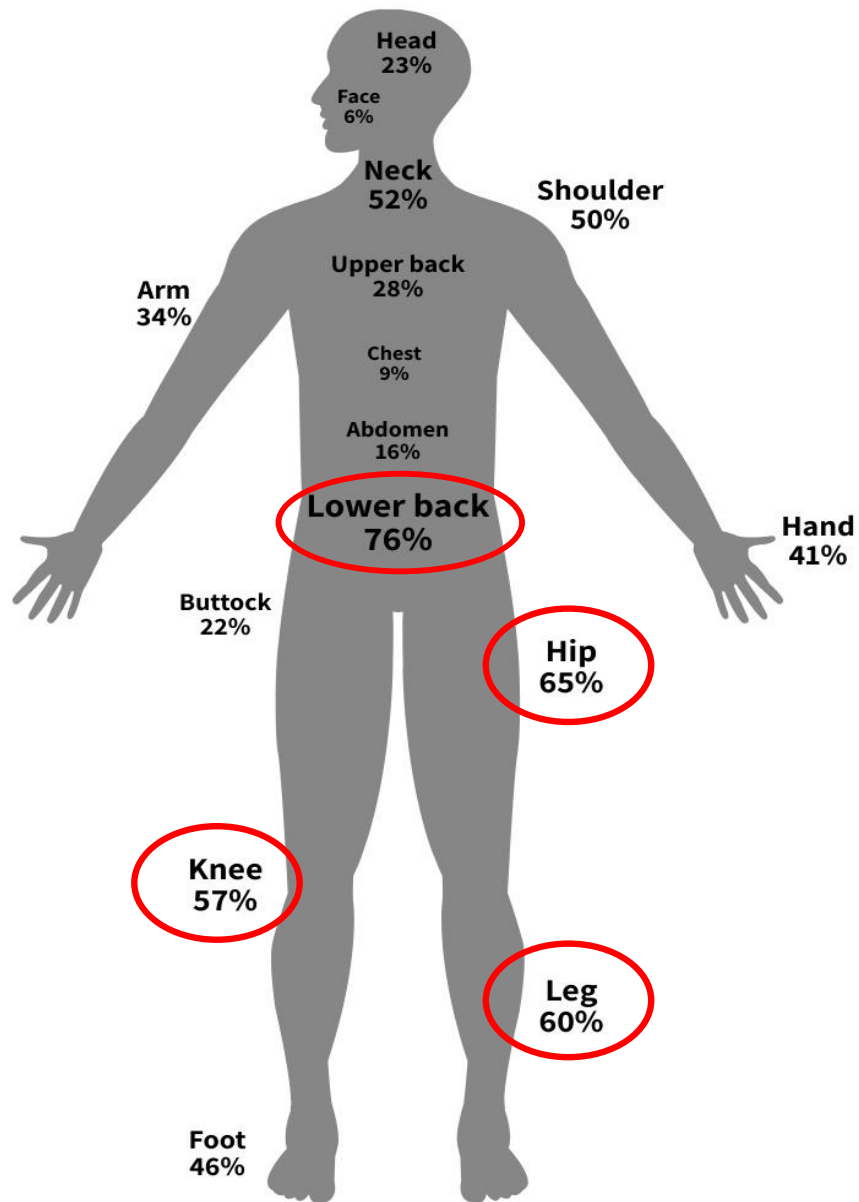
**Patient-reported reasons for functional changes:** Reported as n (%); participants could select more than one reason.

# Results: Chronic Pain

- Among 263 adult participants in Community Registry...
  - 78% (n=205) had chronic pain
  - 73% (n=149) completed the chronic pain survey bundle
- Average age of pain onset
  - **28 years** (SD 15, median 27.5)
- ***Pain intensity did not vary by:***
  - ***GMFCS levels (p=0.18)***
  - ***Age groups (p=0.36)***

**B****BPI: Pain Interference***On a scale of 0-10, 10 being completely, how much does pain interfere with your...*

**Chronic Pain Survey bundle: Brief Pain Inventory (BPI) pain intensity and pain interference results.** Figures display median score and interquartile range among all participants (scale 0-10 for both intensity and interference). Black bar indicates median score; left and right bounds of rectangle indicate 25th and 75th percentile scores, respectively. Minimum and maximum scores for all measures were 0-10, respectively, and thus not included on this figure.



- Average number of pain locations = 8
  - SD 5, range 0-23



**Pain locations.** Percent reporting pain present at each location.

# Results: Pain Treatment

- Room for improvement...
- Rated pain as:
  - **Worse than it was one year ago: 50% (n=77)**
  - **The same as it was one year ago: 40% (n=17)**
  - *Better* than it was one year ago: only 10% (n=17)
- Not well treated:
  - **70%** (n=104) reported having **50% or less pain relief** in the preceding 24h



# Results: Pain Treatment



Don't treat Nociceptive pain

Treatment modalities reported to have helped pain the most were...



Physical therapy  
(20%, n=30)



Over-the-counter medication  
(16%, n=24)



Massage  
(16%, n=24)



Exercise  
(15%, n=22)



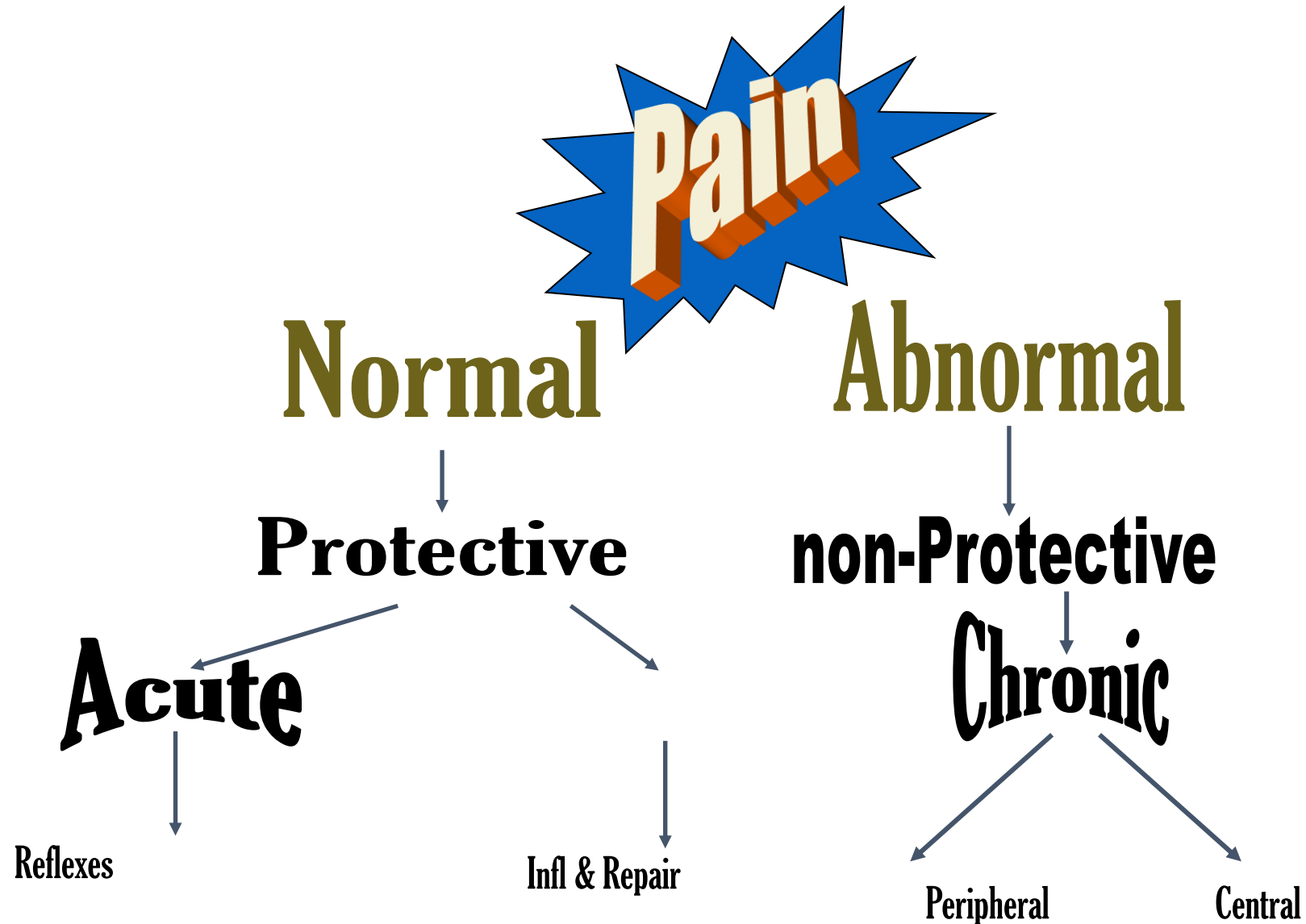
Non-opioid prescription medications  
(14%, n=21)

Different types of pain respond to different treatments

# Pain types and treatments

Mary Gannotti, PT, PhD

# Acute vs. Chronic Pain



# CHRONIC PAIN

- Disease
- 3-6 months, outlasts normal tissue healing time or after noxious stimulus is no longer active
- A persistent complaint of pain without physical cause
- Non protective
- Impairment is greater than would be expected from the physical findings
- Treatment should be multi-professional team

# TYPES OF CHRONIC PAIN

NOCICEPTIVE

NEUROPATHIC

NOCIPLASTIC

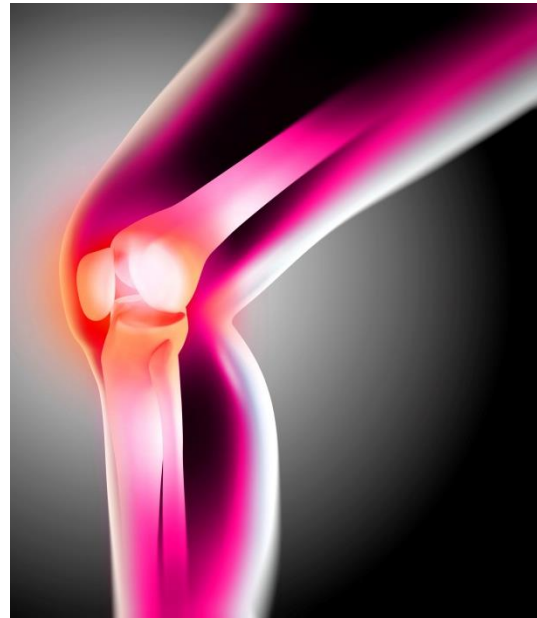
# NOCICEPTIVE

Pain that arises from actual or threatened damage to non-neural tissue and is due to the activation of nociceptors.

- Inflammation
- Mechanical irritation
- Injury



Ankle Sprain



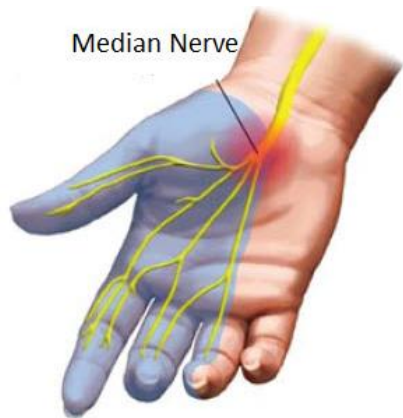
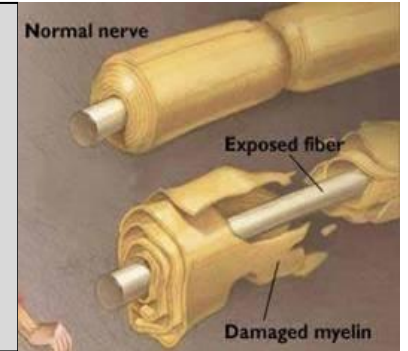
Osteoarthritis



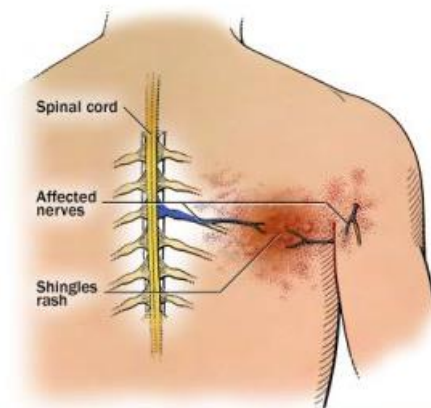
Rheumatoid Arthritis

# NEUROPATHIC

Pain caused by a lesion or disease of the somatosensory nervous system.



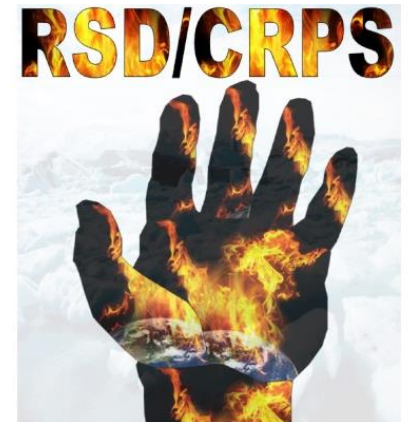
Carpal Tunnel Syndrome



Postherpetic Neuralgia



Diabetic Neuropathy

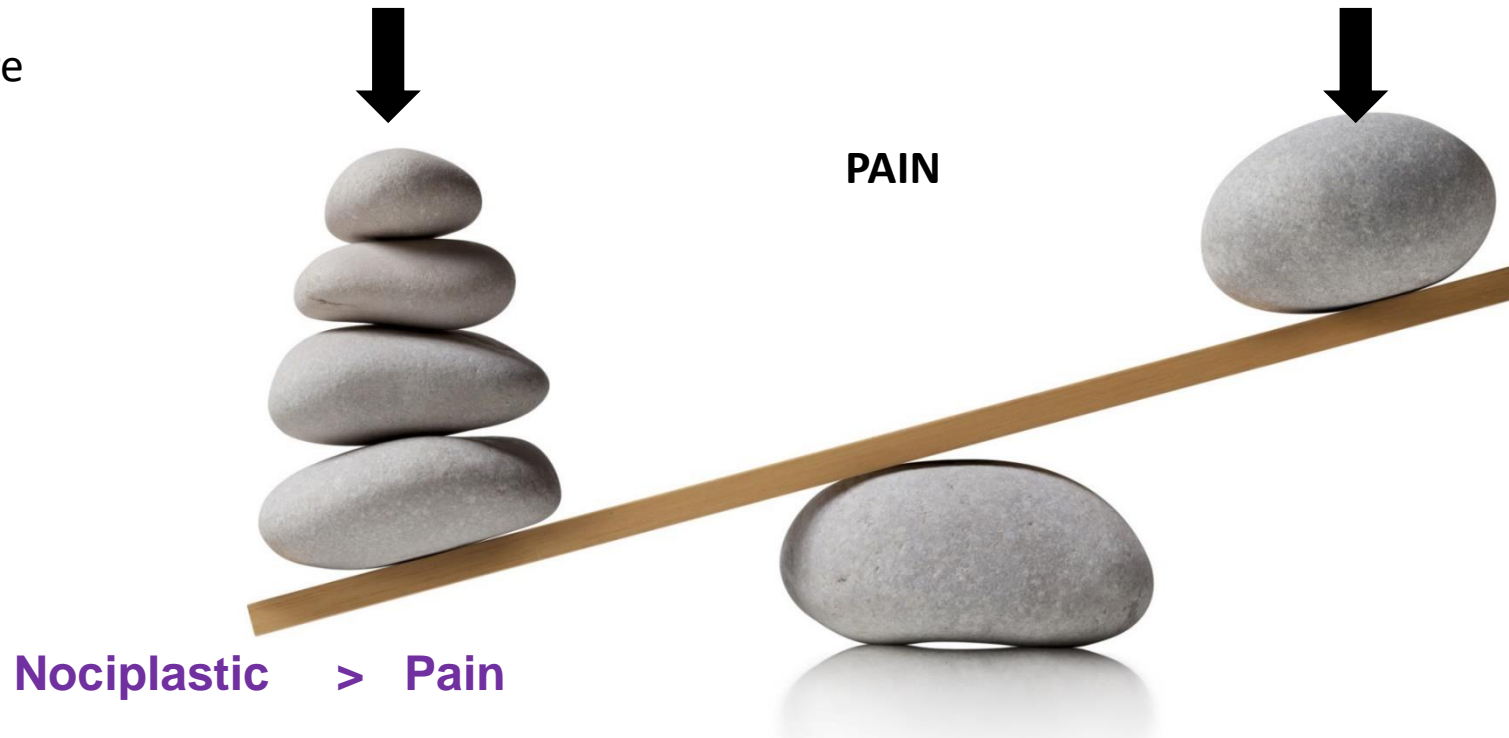


Complex Regional Pain Syndrome

# NOCIPLASTIC

Pain that arises from altered nociception despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain.

Equal pressure





# NOCIPLASTIC



Low back pain



Knee Pain



Carpal Tunnel



Fibromyalgia



TMJ Disorders

# Differentiation of Pain Type



Nocioceptive- Clinical Examination and Patient Response to Treatment



Neuropathic- Clinical Examination, Patient Response to Treatment, Questionnaires, Nerve Conduction Velocity, Quantitative Sensory Testing



Nociplastic- Clinical Examination, Patient Response to Treatment, Questionnaires, Quantitative Sensory Testing

# Treatments



## Pharmacological

Beyond my scope of practice, please call



📞 734-936-7175

<https://www.uofmhealth.org/profile/166/edward-albert-hurvitz-md>



## Non pharmacological

Exercise- anaerobic and aerobic

Mindfulness

Biophysical agents

Weight loss

Posture management

Conservation of joints

ChoosePT™

Provided by APTA

Find a Physical Therapist

<https://www.choosept.com/>



# Exercise- targets all types of pain

- **Chronic Low Back Pain**

- Exercise reduces pain compared to no treatment, usual care or placebo
- Exercise may reduce pain and improve disability compared to common treatments such as electrotherapy or education

[https://www.cochrane.org/CD009790/BACK\\_exercise-treatment-chronic-low-back-pain](https://www.cochrane.org/CD009790/BACK_exercise-treatment-chronic-low-back-pain)



- **Knee Pain from arthritis**

- Exercise shows short term pain reduction (6 months) and long term improved function

<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004376.pub3/full>

- **Increasing Heart Rate provides analgesic effect as well**

Lesnak Pain Rep. 2020



# Mindfulness- Targets Nociceptive Pain

-While mindfulness meditation improves **pain and depression symptoms and quality of life**, *additional well-designed, rigorous, and large-scale RCTs are needed* [Hilton Ann Behav Med. 2017](#)

-Mindfulness shows large effect on treatment of **low back pain**

[Paschali, et al Clin J Pain 2024](#)

-Not clear if it is effective for Knee pain

[Marais et al. E BMCRheumatol 2022](#)



- Mindfulness is **the basic human ability to be fully present, aware of where we are and what we're doing**, and not overly reactive or overwhelmed
- Ways to practice mindfulness
  - *Be Still*
  - *Practice Concentrating on your Breathing*
  - *Have Gratitude*
  - *Observe the sensations in your body*
  - *Move intentionally and concentrate on linking movement with breath*
  - *YOGA-chair yoga, most adaptative form of exercise and the focus is self love*



## NCHPAD's Recent Videos

# NCHPAD VIDEOS

Home » Videos » NCHPAD's Recent Videos



#MiniMeditationMonday



Celebrating 30 years of the ADA



Mindful: A Meditation Series



Home Workouts



Disability and Aging



Disability Employment



Water Wednesday

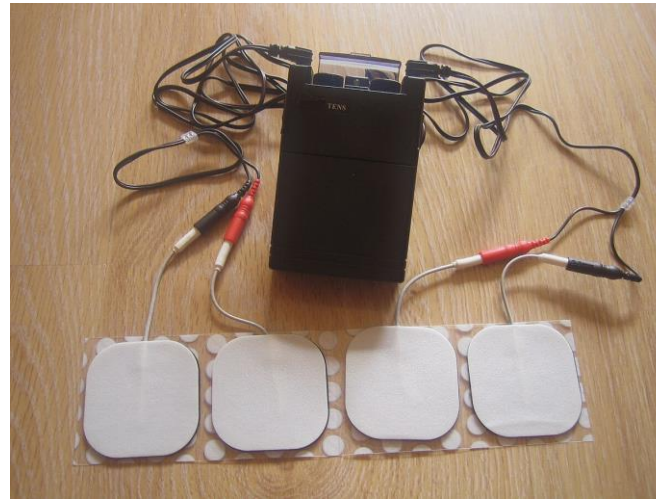


Fitness Recreation Sport

# Biophysical agents- Nociceptive, Nociplastic



Hot Packs, Cold Packs



Transcutaneous Electrical  
Nerve Stimulation (TENS)



Massage



Dry needling

ChoosePT<sup>™</sup>  
Provided by APTA

Find a Physical Therapist



# Maintenance Therapy is Covered By Medicare

- In January 2014, “maintenance therapy will be approved when skilled services are needed to maintain function or prevent or slow deterioration”

	Restorative Therapy	Skilled Maintenance Therapy
Key Components	Typical physical therapy plan: evaluation, goal setting, therapy, and discharge upon reaching maximum potential.	Also known as “compensatory therapy.” Focus: sustain current function and prevent/slow loss of function. <i>Requires the skill of a physical therapist.</i>
Key Considerations	Pros: Addresses immediate needs. Cons: Does not plan for additional episodes of care through the patient’s lifetime.	Pros: Regular, skilled therapy and exercise mitigate effects of physical and cognitive decline. Cons: May increase cost. Difficult in busy clinics.

# Reducing Biomechanical Stresses- all types of pain

<https://www.nchpadconnect.org/>



## Movement Considerations

- Changing lifestyle
- Equipment; bracing
- Use of scooter or human assistance
- Energy conservation
- Exercise purposefully for heart and muscles



### Mindfulness

MENTOR focuses on mindfulness to give you a clear and focused outlook on your wellness journey, allowing you to continue to meet your wellness goals long after the program has ended.



### Exercise

Our wellness program is adapted to your exercise goals and needs, providing comprehensive classes and equipment.



### Nutrition

Proper nutrition is key to good health. Our registered dietitian will help you create a foundation in nutrition to better your health and be mindful about the foods you put in your body.



### Resilience

Our holistic approach to resilience merges mental, physical, and emotional health to optimize the way you live.





# Why Should you join MyCP?

Jodi Kreschemer, MSW

Shannen, Bolde, MPH






Cerebral  
Palsy  
Research  
Network


Optimizing the lifelong health and wellness of people with cerebral palsy and their families through high quality research, education, and community programming.




# Internet Presence for Broad Community

Engaging the Cerebral Palsy Community in Research That Matters

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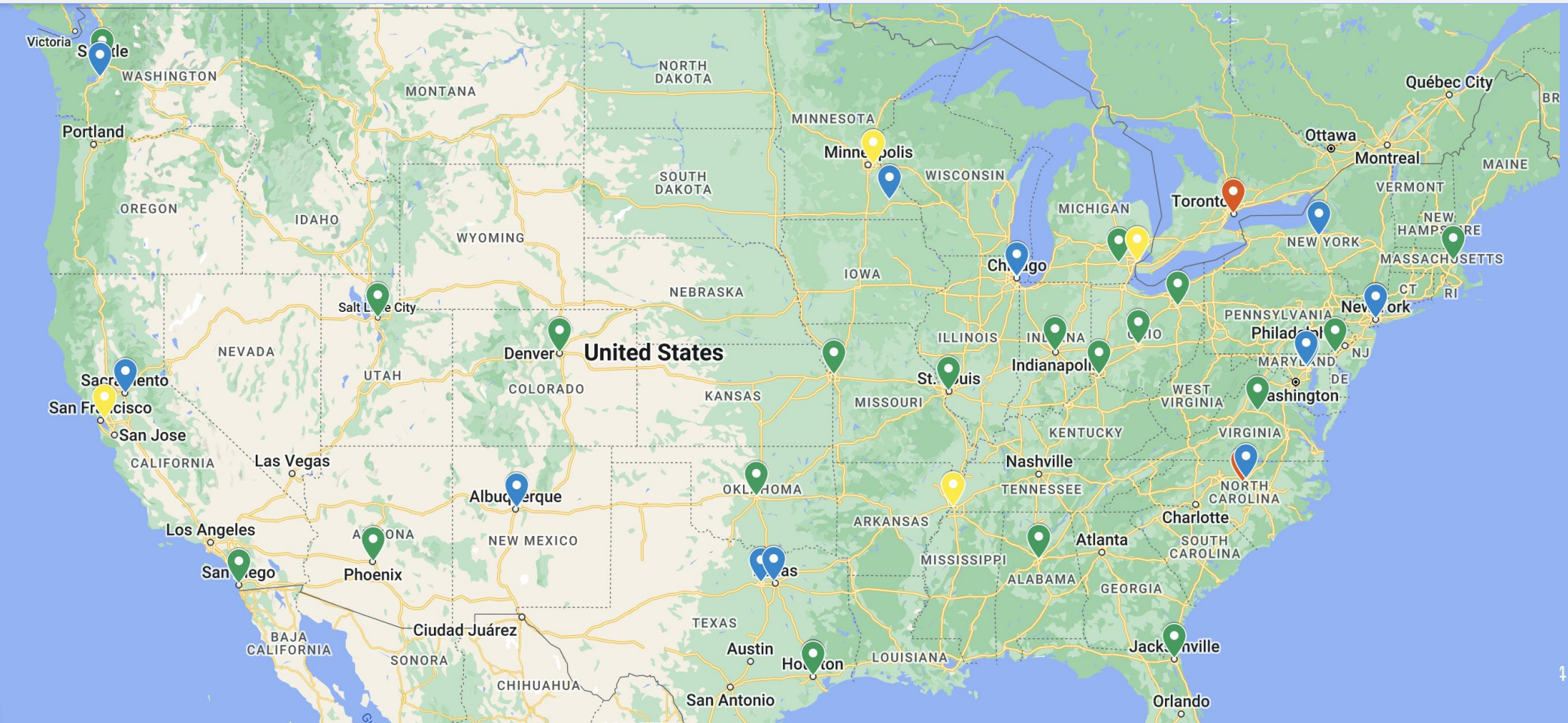


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# 30+ Center Learning Health Network

- 📍 Enrolling patients
- 📍 Preparing registry
- 📍 Compliance and IT
- 📍 Candidate sites





# NETWORK FOCI

## Clinical Research

- Spasticity Management Non ambulatory
- Surgery Outcomes
- Shared Decision Making
- Nutrition and Body Composition

## Quality Improvement

- Transition to Adulthood
- Dystonia Management
- Hip Surveillance
- Adult Pain Screening & Classification

## Education/Resources

- CP Tool Kit
- Adult Tool Kit in progress (Fall 2024)
- Webinars
- Forum
- **Mindfulness, Exercise, Nutrition, to Optimize Resilience**

# YOU CAN PARTICIPATE: JOIN MYCP.ORG

Engaging the Cerebral Palsy Community in Research That Matters

Donate

Blog

Shop

Join MyCP ▾



Cerebral Palsy

Adults with Cerebral Palsy

Cerebral Palsy Research

Clinicians & Researchers

About Us

## MyCP

MyCP is a free, private and personal portal into the CP Research Network for:

- personalized educational recommendations,
- exclusive content,
- research participation,
- discussions,
- and free fitness programs.



Participate in discussions or research on CP.

Join

Log in

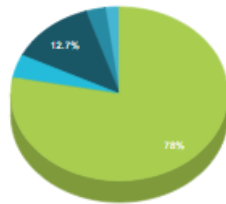


# Be Part of Network of Consumers, Caregivers, and Allies- MyCP.com

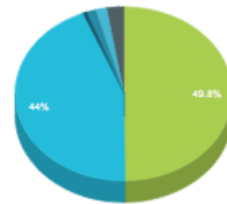
## MyCP Surveys

Below you will find links to your consent form and any available research surveys that you may take. The surveys will not appear until you have completed your consent. You may revisit your consent at any time to print it or revoke your consent if you are so inclined. The research surveys appear conditionally based on your demographics and characteristics of your [cerebral palsy](#). At any given time, there may be zero or multiple surveys available for you to complete.

Total MyCP Members: **3261**



- Person/Caregiver: 2541
- Advocate: 141
- Provider: 413
- Researcher: 95
- Industry: 69

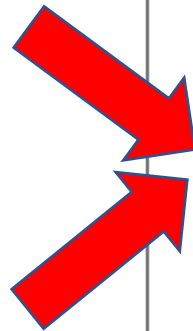
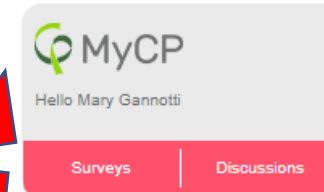


- Self: 1268
- Parent: 1117
- Spouse/Partner: 15
- Sibling: 35
- Caregiver: 43
- Other Relative: 65

### What is Informed Consent?

Your "Informed Consent" gives us permission to include your data in a study. It is "informed" because we will provide you with information about the studies, whether there are any risks or benefits, and to make sure you know that your participation is voluntary.

Only parents and adoptive parents may enroll a child under 18 years of age.

MyCP  
Hello Mary Gannotti

Surveys | Discussions



# Why take the Surveys on Function & Pain?

- Learn more about yourself
- You get score that show you how you compare to other people with cerebral palsy like you
- Helping others by contributing to research
- Joining a community where you can get information, webinars, research, connections with other people, other clinicians.
  - Email other people on Forum and have questions ask.
  - Be part of something that is making a difference



Go to:

<https://cprn.org/mycp/joinmycp/>



Consumers can track their own functional changes and pain over time in relation to themselves and others in the community as percentile scores are generated and a pdf summary scores emailed

Providers can use these measures as part of clinical care planning and tracking

Creating source of data for secondary analysis by interested researchers and clinicians





Questions & Discussion

# Thank you!



Questions?



Edward Hurvtiz, MD



Jodi Kreschemer, MSW



Shannen Bolde, MPH



Mary Gannotti, PT, PhD

[Gannotti@hartford.edu](mailto:Gannotti@hartford.edu)