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**Complex Regional Pain Syndrome,  
Fibromyalgia  
&  
Amplified Pain Syndromes**

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**DISCLOSURE**

**Relevant Financial Relationships**

**None**

**Off Label Usage**

**None**

**Industry Acknowledgment**

**None**

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## Learning Objectives

1. Recognize the different clinical patterns of pain in amplified musculoskeletal pain (e.g., with and without overt autonomic changes)
2. Understand how to check for allodynia
3. Understand the principles behind and the outcome of a therapeutic exercise program
4. Identify the characteristic profile of children with amplified musculoskeletal pain

- ❖ Who are these kids?
- ❖ How to establish a diagnosis?
- ❖ How do we explain it?
- ❖ How do we treat it?
- ❖ Does it work?

## **PAIN**

- **Definitions are important**

## **PAIN**

- **An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage**
- **Pain is always subjective**



## PAIN TERMS

- **ALLODYNIA**
  - pain due to stimulus that does not normally provoke pain
- **HYPERALGESIA**
  - an increased response to a stimulus that is normally painful
- **HYPERESTHESIA**
  - allodynia and hyperalgesia

## STORIES

- 12 y.o. girl with cold, blue foot, no sock, on crutches and pain spreading up leg/hand
- 13 y.o. girl cannot bend her knee or walk and cannot read (can see)
- 8 y.o. boy cannot go to school after playing soccer - crawls about home
- 12 y.o. girl who cannot sit down for 2 years
- 13 y.o. boy with shoulder pain after basketball & traveling pains
- 14 y.o. girl with 1 year widespread pain, +ROS, poor sleep, depressed

all are suffering

## Amplified Pain Syndromes

Fibro &  
total  
body

All can be hypervigilant

Intermittent

CRPS1

No autonomic  
changes –  
localized & diffuse

## Sleep

- Poor sleep, little sleep, unrested.
- Is it a disorder or a complaint?
- They do not fall asleep in school.

## Alpha-delta sleep in fibromyalgia

	Alpha delta sleep (minutes)	Alpha-delta sleep (% of total slow wave sleep)	Total sleep time (minutes)
Patients, pre-treatment	60	70	397
Patients, post-treatment	56	74	409
Controls	17	22	454

	Pre treatment	Post treatment	P
Sleep difficulty (100 worse)	55	21	0.008
Lack of Energy (100 worse)	62	16	0.001

Sleep 2013;36(4):509-516.

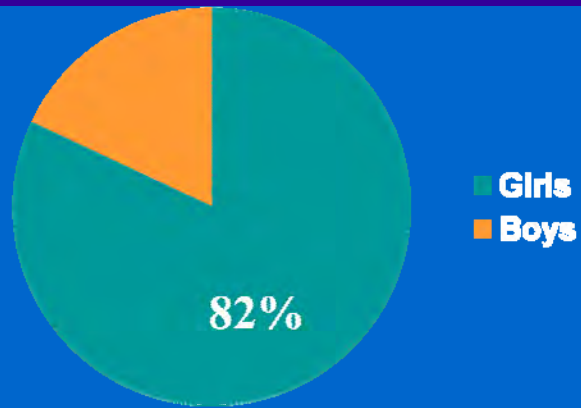
## Sleep

- Sleep hygiene
  - No caffeine – soda, tea, coffee
  - No exercise for 2-3 hours before bedtime
  - No TV, radio
  - If don't get to sleep in 30 minutes, get up and do something non-stimulating
- Fix the sleep and you WILL NOT fix the pain – sleep apnea folks do not hurt
- Medication does not help but it will make it your problem to fix them

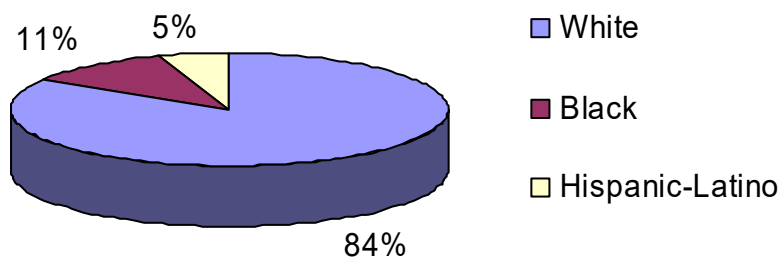
## Amplified Pain

- Females
- Mean age 12 years
- Mean duration is > 1 year
- Most have constant pain
- Pain may be in multiple sites

## Sex

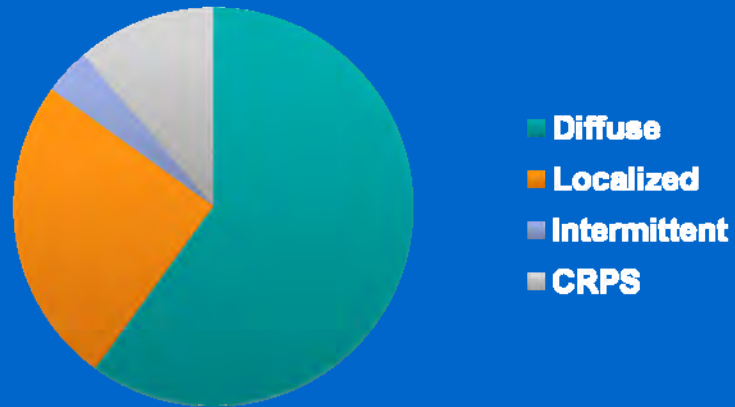


## Race

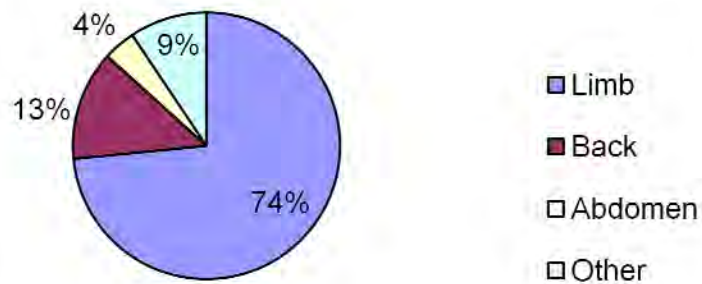




## Forms of Amplified Pain



## Localized Pain Location



## Historical Clues

- Increasing pain over time
- Worse with rest, cast, splint
- Failed all prior therapy or side effects

## Past Medical History Clues

- Slow healer
- Positive Review of Symptoms
- High level athlete or dancer

## Social History Clues

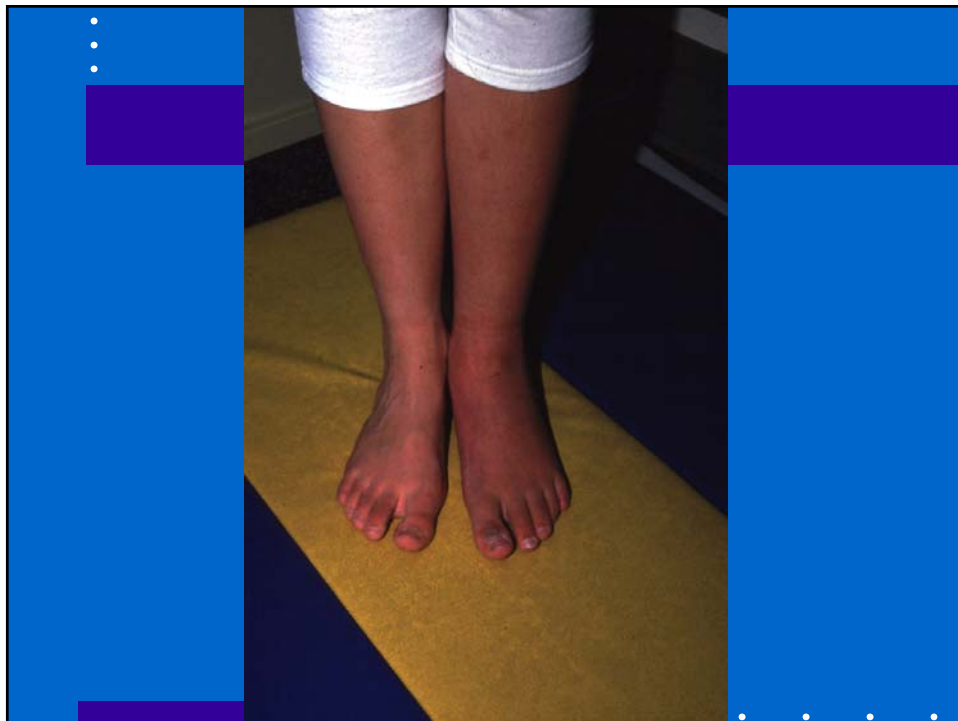
- Major life events
- Role model for chronic pain
- Typical personality
  - mature
  - excels
  - pleaser
  - perfectionistic

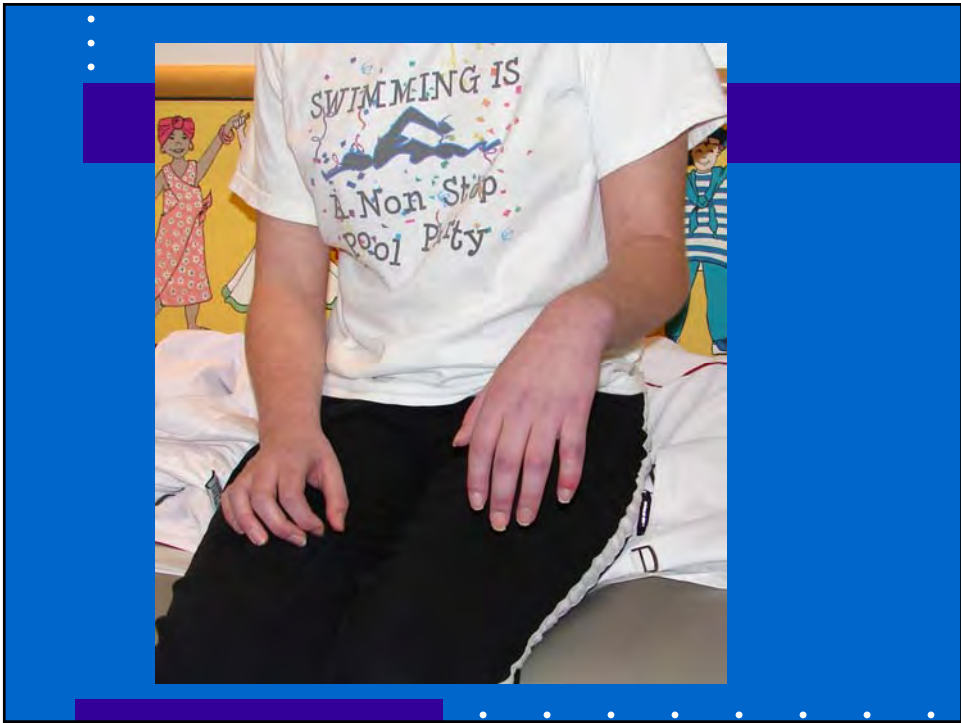
## Physical Exam Clues

- Spokes-mother
- Pseudo-mature
- Incongruent affect
- La belle indifference
- **Enmeshment** – very subjective

## Autonomic Signs

- Cold
- Cyanotic
- Clammy
- Decreased pulse
- **CHECK AFTER EXERCISE**
- Dystrophic skin









## Trigger Points

### Hard to know what they mean

occiput	lateral C-spine
trapezius	2 <sup>nd</sup> rib
scapula	epitrochlear
gluteal fold	posterior greater
trochanter	medial knee

**Need 3 months of widespread pain to apply**

## Now painful areas

shoulder girdle upper arm  
lower arm                      buttocks/trochanter  
upper leg                      lower leg  
jaw                      upper back  
lower back                      chest  
abdomen                      neck

**Need 3 months of widespread pain to apply  
PLUS**

## Symptoms

fatigue                      unrefreshed sleep  
cognitive                      irritable bowel  
abdominal pain                      hair loss  
hives                      urinary frequency  
numbness                      chest pain  
bruising                      Raynaud  
blurred vision                      nervousness  
dry mouth                      dizziness  
etcetera, etcetera, etcetera



## Check for Conversion

- Stiffness
- Paralyzed
- Shaking
- Conversion gait
- Non epileptic spells
- Blind, deaf, memory loss

## Conversion in Fibromyalgia

45 of 64 (70%)



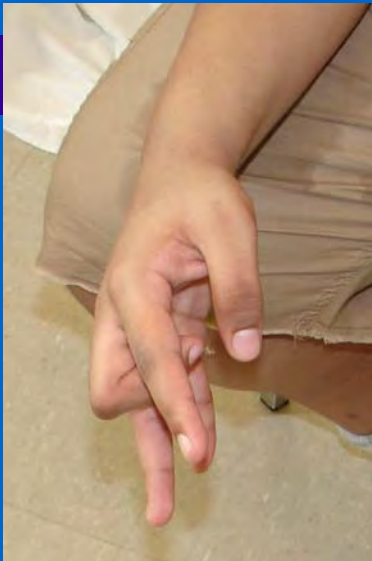
**After 11  
days  
ketamine  
coma and  
40  
boosters**



**Conversion  
fist**



**Post spinal  
cord  
stimulator  
and  
conversion  
plantar  
flexion**



**Pain and conversion**

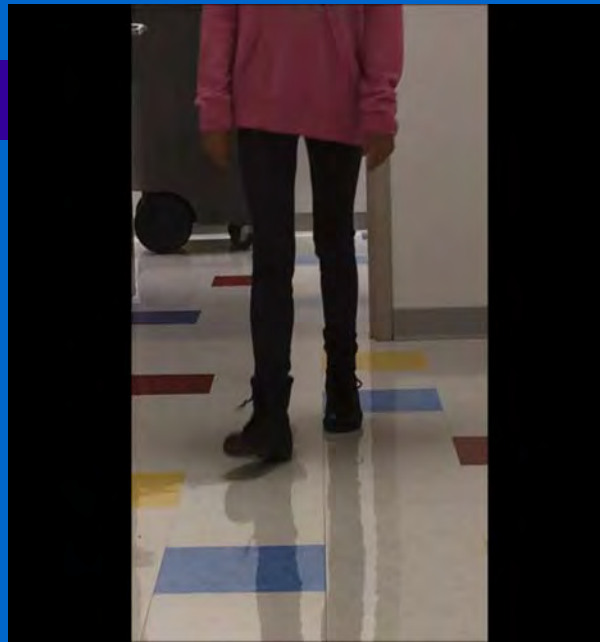
## Conversion symptoms seen

Motor, stiffness	29	Memory loss	3
Gait (astasia-abasia)	14	Weakness	3
Dizziness	8	Blindness	2
Motor, paralysis	7	Coma	2
Twitching, shaking	6	Breathing symptoms	1
Loss of voice	5	Inability to eat	1
Numbness	5	Regression	1
Pseudo-seizures	4	(Self mutilation)	5

## Could not write:

It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of light, it was the season of darkness, it was the spring of hope, it was the winter of despair, we had everything before us, we had nothing before us, we were all going direct to heaven, we were all going direct the other way, in short, the period was as far like the present period, that some of its noisiest authorities insisted upon it being received, for good or for evil, in the superlative degree of comparison only.

# Cutting

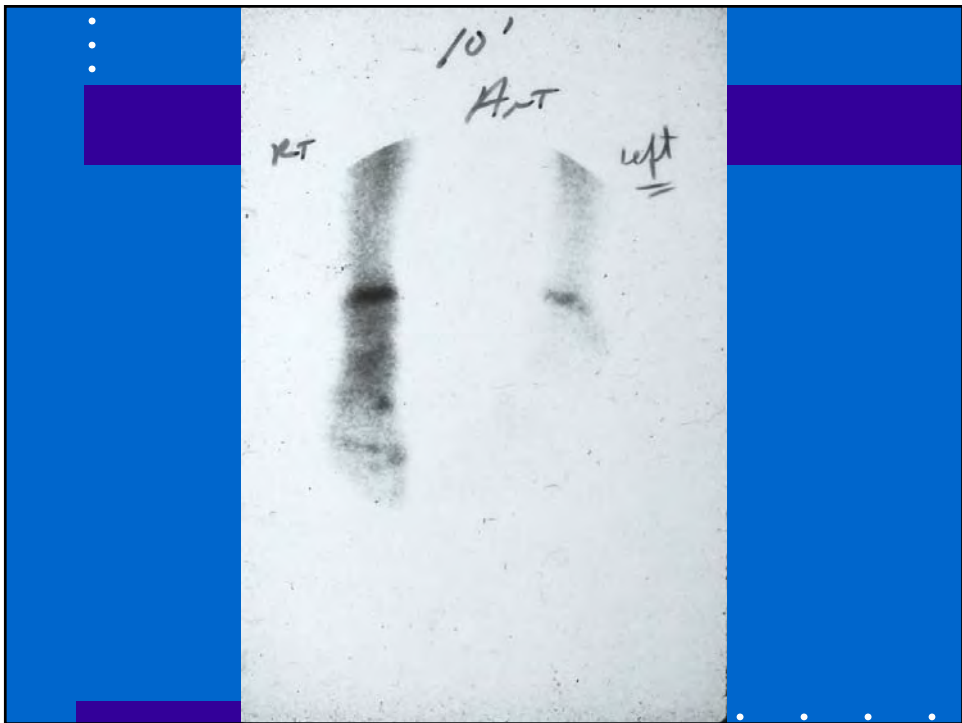
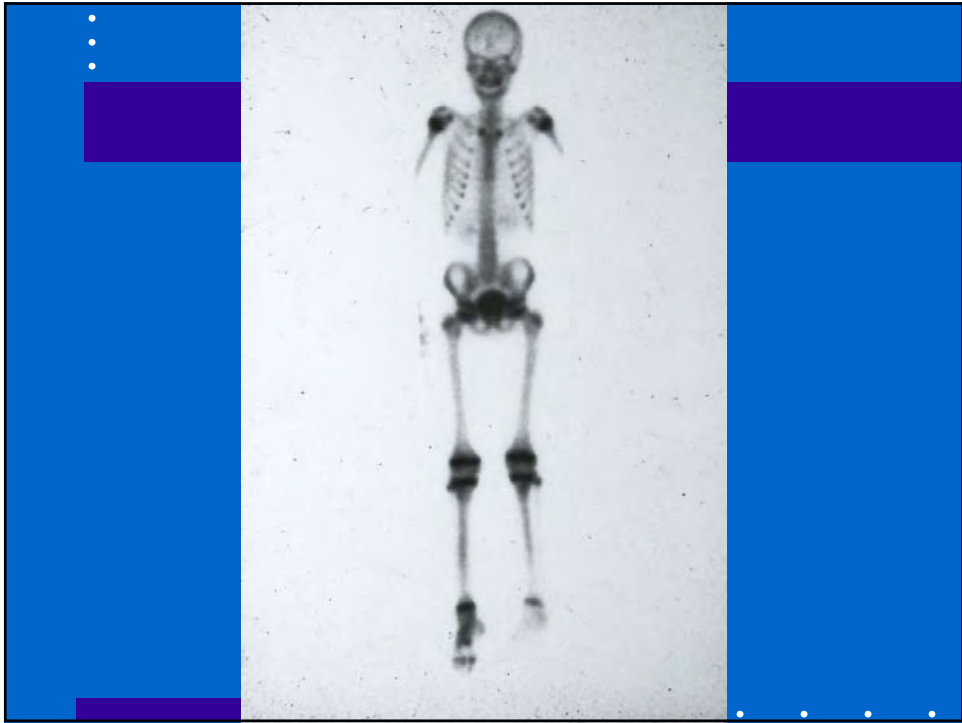


## Allodynia

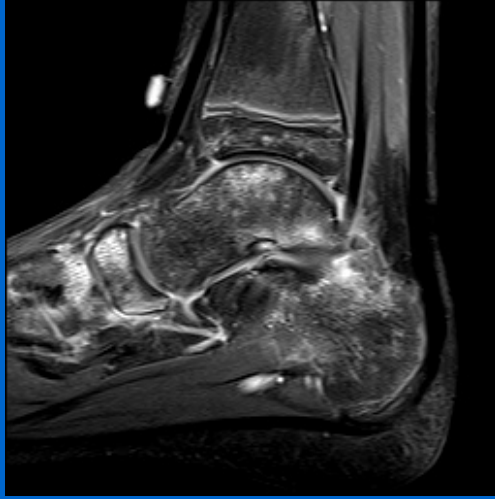
- Light touch
- Gentle pinch of a fold of skin
- **CHECK BORDERS REPEATEDLY**
  - may vary 4 to 12 cm within seconds

## Laboratory Studies

- **Blood studies**
  - normal
- **Radiographs**
  - normal or osteoporosis
- **Bone Scan**
  - decreased
  - can be normal or spotty (adult-like)
- **MRI**
  - edema – soft tissue & bone



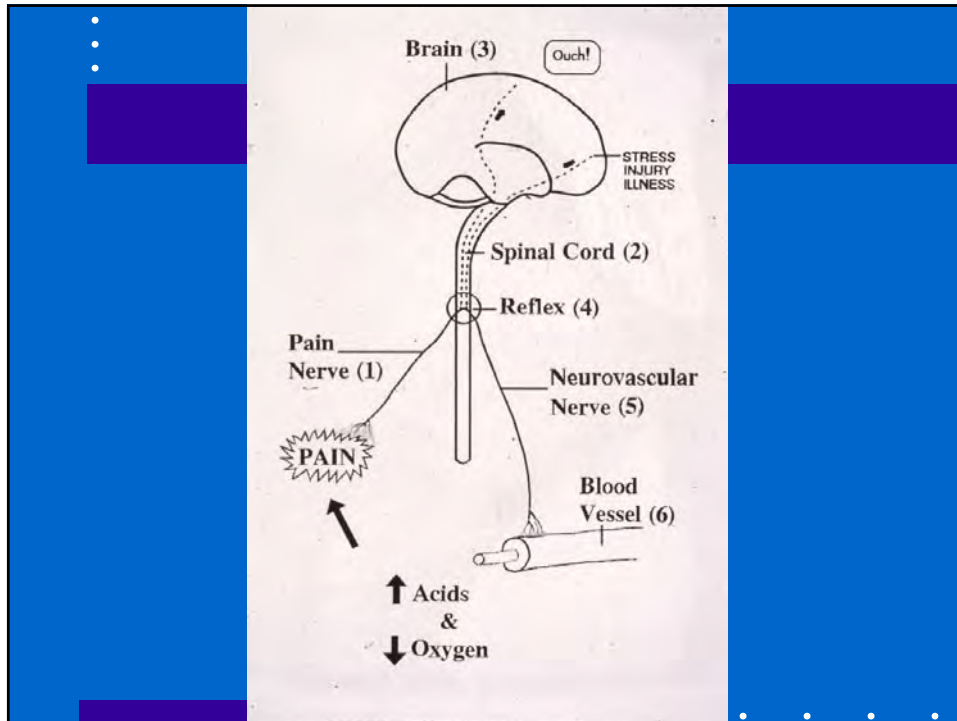
## MRI – bony edema



## Working Model of Pain

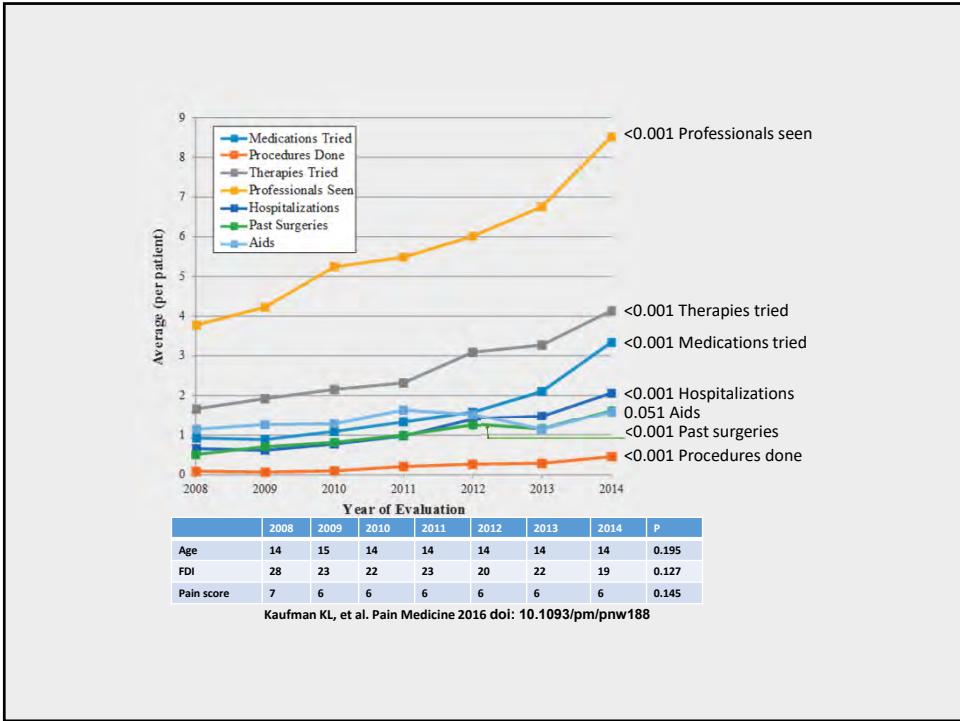
- Makes the pain **understandable** (real)
- They are not faking it
- Pain can arise from:
  - injury
  - illness
  - psychological stress





## Treatment

- Discontinue medical investigations
- Discontinue medications



# Treatment

- MORE EXERCISE THAN YOU CAN IMAGINE
- DESENSITIZATION

## Exercise Therapy

- 5-6 hours a day of PT/OT
- Continuous aerobic activities
- Focus on function - real activities
- Desensitization
  - towel and lotion rubs
  - massage

## Outcome

- Within 1-2 weeks 80% fully functional
- Within 1st month 95% fully functional
- Within 1st month 75% pain free
- ~10% fail - need psychotherapy before they can allow themselves to get better
- Clinical Journal of Pain 1999;15:218-23

## Outcome - CRPS 103 Patients

- **103 patients treated with exercises**
  - 95 (92%) resolved their pain and function
  - VAS initially 76 out of 100 maximum
    - Those in remission (n=77): 1
      - 3-20 in 8 children with overuse/mechanical pains
    - those not in remission (n=7): 58
- **49 followed for over 2 year (mean 5y3m)**
  - 43 (88%) had no symptoms of CRPS
- Clinical Journal of Pain 1999;15:218-23

## Outcome - CRPS 103 Patients

- **Relapses**
  - 15 of 49 (31%) had relapses (some without autonomic signs)
  - median time to relapse was 2 months, 79% were within first 6 months
  - most resolved quickly with reintroduction of exercise (half at home by self and half at hospital with PT/OT)
- Clinical Journal of Pain 1999;15:218-23

## Outcome - CRPS 32 patients

- **Portland/Pittsburgh**
  - 89 % no pain
  - 95% full function in 2 months
  - 7 recurred – 5 treated themselves

PMR 2012;4:349-54

## Outcome - CRPS 56 Patients

- **Boston**
- **Old study with drugs 70 patients**
  - 42% significantly better
- **New study 56 patients**
  - 95% significantly better

J Bone Joint Surg AM 1992 74:910-9  
Clin J Pain 2012 28:766-74



**After 5 months  
and 8 blocks**

7 days later  
with just  
exercise  
therapy



Fibromyalgia (diffuse) 10 patients - sleep study

	Baseline	post-Rx	P
FDI	31	4	.004
Pain VAS (100 mm)	65	17	.000

Functional disability inventory 0-12 normal  
13-28 moderately disabled  
29+ severely disabled

Sleep 2013;36(4):509-516.

## Fibromyalgia 64 patients – 1 year outcome

	Entry	Exit	1 year F/U	P entry/end	P end/1yr
FDI	24	7	5	<.001	.12
Pain VAS	66	25	20	<.001	.05
BOT-2 total	24	54	69	<.001	.05
Bruce	9.8	13.4	12.5	<.001	.005
Peds QL	48	66	78	<.001	<.001
Physical health	31	63	78	<.001	<.001
Emotional	50	60	75	<.001	.070
Social	70	85	90	<.001	.140
School	50	55	80	.002	<.001

J Pediatr 2015;167(3):731-737 Mean age 16 years, 94% girls, 95% white

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## Outcome other symptoms

- Suicide attempts
- Eating disorders
- Other body pains
  - abdomen, head, sinus, eye, teeth
- Conversion disorders
  - paralysis, blind, pseudoseizures

Age	N	patients with suicidal thoughts only N (%)	patients with suicidal attempts N (%)	Total patients with suicidality N (%)
11	65	10 (15%)	2 (3%)	12 (19%)
12	93	10 (11%)	0 (0%)	10 (11%)
13	85	10 (12%)	1 (1%)	11 (13%)
14	123	14 (11%)	3 (2%)	17 (14%)
15	142	24 (17%)	1 (1%)	25 (18%)
16	152	27 (18%)	4 (3%)	31 (20%)
17	96	15 (16%)	6 (6%)	21 (22%)
<b>Total</b>	<b>756</b>	<b>110 (15%)</b>	<b>17 (2%)</b>	<b>127 (17%)</b>

## Stress?

- It is Okay to talk about stress
- Most parents are very interested in their child's emotional wellbeing
- After discussing it in a straightforward manner, you might learn more than you want to
- Need to talk about conversion matter of fact fashion

## Stresses

- Most are issue identification
- Family dynamic dysfunction
- Martial discord (covert > overt)
- School avoidance
- Abuse - sexual/physical/emotional
- RARELY depressed (10%)

## Counseling

- Not traditional pain counseling
- People who go to counseling are not dumb or crazy
- Counselors are experts in feelings and emotions
- What do you tell a counselor?

**What you really,  
really DO NOT want  
to tell him or her**

## What is a country doctor to do?

- Recognize it
- No further investigations unless absolutely indicated
- Sympathize and acknowledge the pain as real but resist urge to throw medications at pain and sleep
- Work with a physiotherapist to get the child moving – despite pain
- Discuss stress and have it addressed
- Follow-up in a month

## Final Analysis

- Great kids who are in **real need**
- We can significantly not only address their symptoms (**short term benefit**) but also address psychological dysfunction (**long term benefit**)
- Very time consuming – for entire team
- Very rewarding

Thank you



References in handout



StopChildhoodPain.org  
Free code: painfree