# RSDSA Sponsored Research

1992 to present

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~\$1,960,000

# Mechanisms of Disease Diagnosis & Classification Treatment

#### Mechanism of Disease

**Early Efforts** 

Model development

Neural mechanism

Adrenergic mechanisms

More Recently

Cytokines

Autoimmune determinants

**Epigenetic determinants** 

### Diagnosis & Classification

#### **Early Efforts**

Hypersensitivity and visceral pain

Population studies

Pain perception

Major histocompatibility

The Budapest Criteria

Salivary Oxidation products

### Diagnosis & Classification

# More Recently

A Severity Score

Defining "Recovery"

A Core Data Set for clinical research

Maternal mitrochondria

#### **Treatment**

#### **Early Efforts**

Surgical sympathectomy

Transcranial stimulation

**Nitroglycerine** 

Evidence-based clinical practice guidelines

#### **Treatment**

# More Recently

Low dose naltrexone
Nitrous Oxide
Induced sensory-motor adaptation
Ketamine infusion consensus guidelines

# "20" Year Study of the Long Term Health Effects of CRPS

Peter A. Moskovitz

Denver, CO October 26, 2019

#### Why?

Because people with CRPS feel that their disease is about more than the pain.

Because other, "unrelated" health problems aren't unrelated.

#### How Come?

My theory: CRPS is an immune mediated disease.

Immune impairments have global effects.

#### Neuroinflammation (NI)

A collection of diseases (this is just a few):

Irritable Bowel Disease: NI of the intrinsic control of the gut

Interstiticial Cystitis: NI of the bladder

ALS and related degenerative diseases: NI of the motor apparatus

Multiple Sclerosis: NI of the myelin apparatus (motor and sensory)

Fibromyalgia: NI of the proprioceptive apparatus

CRPS: NI of the nociceptive apparatus

#### Questions

What is the incidence of adverse health events in people with CRPS over time?

Are adverse health events related to the type or course of CRPS?

### Study Design

An Internet based survey
An unselected sample of people with a diagnosis of CRPS
A 9-part questionnaire, completed annually for 20 years

#### The Study Questionnaire

**Demographics** 

1 CRPS history

Family history

**Spread or Progression** 

Remission

2 Pain Experience

3 McGill Pain Questionnaire

4 Review of systems check-list

5 Medications

6 Care utilization

7 Profile of mood states

8 Pain disability index

9 SF-36

#### Data Management

Professional Data Management Company Dedicated, secure research website Privacy assurance Safety protocols

#### The Study Team

Peter Moskovitz, Washington, DC – Principle Investigator Kyoko Rice, Los Angeles, CA – Project Manager Jim Broatch, Milford, CT – Project Administrator Albert Farias, Los Angeles, CA - Biostatistician

#### The Glitch

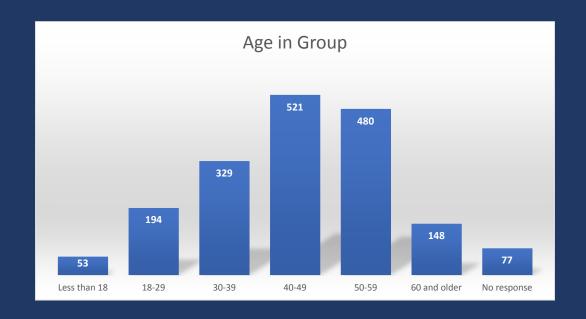
There is no type nor sort of good idea that cannot be monetized to the benefit of the developer and for the exploitation of everyone else.

#### Who Responded?

# Mostly whom you'd expect: White women

Does this imply a genetic predisposition to the disease – probably.

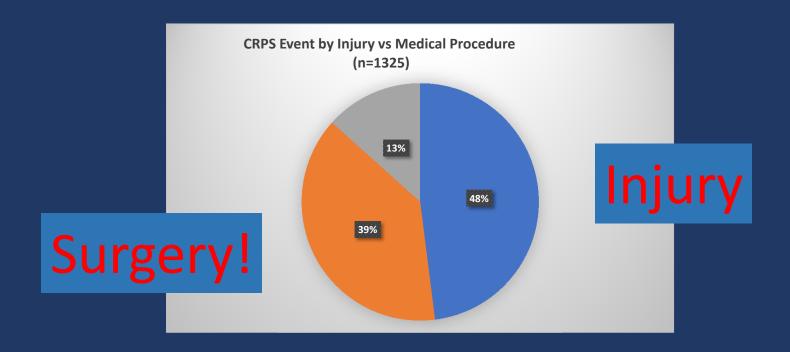
# 1802 Respondents



#### Where did CRPS start?

Lower extremity more than upper.
Only 5% non-extremity CRPS
Right (dominant?) side slightly > than left.

#### What "caused" it?



#### Who first suggested CRPS?

Appropriately enough, 45% reported it was an Orthopaedic Surgeon.

3% reported that their own research suggested CRPS.

#### Can CRPS spread to other sites?

87% reported that their CRPS spread.

#### Does spread only occur early?

42% reported that their CRPS spread occurred more than a year after onset.

# Does our cohort represent the population of people with CRPS?

Probably not.

Our respondents appear to have a more severe type or sort of CRPS.

# Compared to "population-based" cohorts of people with CRPS:

Our respondents had:
A lower incidence of remission
more spread and
reported less adequate pain control.

#### But there's some good news.

Although the experience of pain didn't change much over time, respondents reported improved Quality-of-life (SF-36).

#### The Take-Home.

Coping with CRPS and adapting to the experience of chronic pain is possible. The stuff you learn here and from RSDSA works.