RSDSA Sponsored Research

1992 to present
RSDSA Sponsored Research

~$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
- Interstitial 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

Age in Group

- Less than 18: 53
- 18-29: 194
- 30-39: 329
- 40-49: 521
- 50-59: 480
- 60 and older: 148
- No response: 77
Where did CRPS start?

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

CRPS Event by Injury vs Medical Procedure (n=1325)

- Injury: 48%
- Surgery: 39%
- Other: 13%
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.