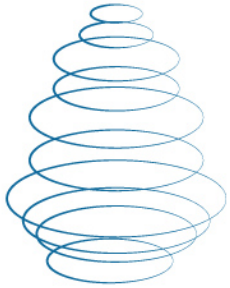


Simmaron Research

Scientifically Redefining ME/CFS

Presented to CFSAC, June 28-29, 2017

by Courtney Miller, Board President

Simmaron Research: Goals

- Redefine ME/CFS through science
- Determine diagnostic markers
- Identify scientific characteristics of subsets of ME/CFS patients
- Pursue research that can lead to potential treatments
- Marry clinical and scientific expertise in translational research
- Improve the lives and health of patients

Simmaron Research

Simmaron Research: Mission

- Play a key role in scientific research to improve diagnosis and treatment of ME/CFS patients
- Help fund and coordinate pilot studies to determine diagnostic markers, patient subsets, and potential treatments
- Publish peer-reviewed findings and share results openly
- Collaborate

Simmaron Research

History of Simmaron

- Simmaron was founded in 2011 by ME/CFS patients in Northern Nevada.
- Harnesses the 30-year clinical expertise of Dr. Dan Peterson, Scientific Advisor
- Access to:
  - Well-characterized patient population for studies
  - Wealth of data for mining
  - Unmatched biobank of patient samples
  - Strategies driven by patient care

Simmaron Research

How We Function

- Foundation is run by volunteers
- Regularly fund research staff – manager, coordinators, interns
- Some collaborators we fund to do studies that are strategic to our goals
  - Spinal fluid studies
- Other collaborations, we staff the work

Simmaron Research

Scientific Advisory Board

- Dan Peterson, MD, Sierra Internal Medicine
- Mady Hornig, MD PhD, Columbia University Center for Infection and Immunity
- Konstance Knox, PhD, Coppe Healthcare
- Maureen Hanson, PhD, Cornell University

Simmaron Research

Simmaron's Scope

Since 2011:

- Funded ~ $1 million of research work
- ~15 peer reviewed articles published by Scientific Advisors
- Provided expert input to FDA, NIH, IOM, CDC
- Collaborated with CDC, Columbia Univ., Griffith Univ., University of Nevada Reno, SUNY-Albany, Chronic Fatigue Initiative

Simmaron Research

Accomplishments

- Helped drive a strategic focus on immunological studies
- Signature spinal fluid studies with published findings that reinforced immunological research
- Collaborated in publishing subset findings:
  - Short duration v long duration
  - Classical v atypical cases
  - ME with and without Irritable Bowel Syndrome

Simmaron Research

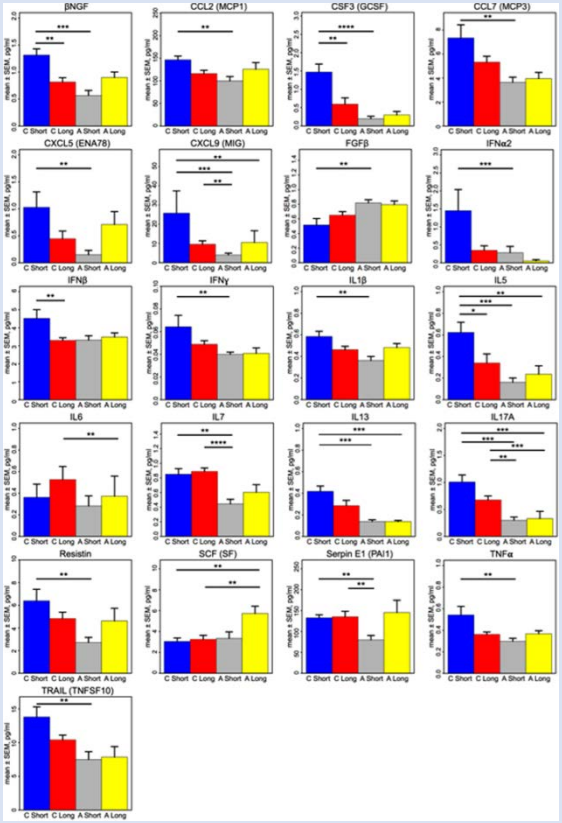
3 collaborative publications in the last 2 months

Simmaron Research

Spinal Fluid Results

Columbia's CII published 2nd peer-reviewed article from Simmaron spinal fluid studies

- Identified distinct classical and atypical immune profiles



M Hornig, CG Gottschalk, ML Eddy, X Che, JE Ukaigwe, DL Peterson and WI Lipkin.

Immune network analysis of cerebrospinal fluid in myalgic encephalomyelitis /chronic fatigue syndrome with atypical and classical presentations.

Translational Psychiatry (2017) 7, e1080; doi:10.1038/tp.2017.44; published online 4 April 2017

CDC Multi-site Study

1st publication from the CDC's Multi-site Clinical Assessment Study

Unger ER, Lin JS, Tian H, Natelson BH, Lange G, Vu D, Blate M, Klimas NG, Balbin EG, Bateman L, Allen A, Lapp CW, Springs W, Kogelnik AM, Phan CC, Danver J, Podell RN, Fitzpatrick T, Peterson DL, Gottschalk CG, Rajeevan MS,

MCAM Study Group. Multi-Site Clinical Assessment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (MCAM): Design and Implementation of a Prospective/Retrospective Rolling Cohort Study.

American Journal of Epidemiology (2017) 185 (8): 617-626. DOI: https://doi.org/10.1093/aje/kwx029 17 March 2017

"The strength of this study's design lies in the expertise of the clinicians who recruited patients."

Microbiome Collaboration

4 site Microbiome study published initial findings by Columbia's CII

- Differing microbiota profiles in ME/CFS + IBS vs ME/CFS – IBS

Reduced levels of good bacteria in ME/CFS

M Hornig, Nagy-Szakal D, Williams BL, Mishra N, Che X, Lee B, Bateman L, Klimas NG, Komaroff AL, Levine S, Montoya JG, Peterson DL, K Jain, ML Eddy, WI Lipkin.

Fecal metagenomic profiles in subgroups of patients with myalgic encephalomyelitis/chronic fatigue syndrome

Microbiome 2017 **5**:44 **DOI:** 10.1186/s40168-017-0261-y

The Promise of Treatments

- Treatment is the most pressing unmet need
- We all have to build the field of evidence-based treatments collaboratively
- Treatment trials are all but non-existent
- The field needs to study responders to Ampligen, cidofovir, antivirals, rituximab, etc
- Simmaron can do its part
- Everyone on this committee has a part to do.

More information

www.simmaronresearch.com

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