



Solve ME/CFS Initiative

Leveraging patient-centered
research to cure ME/CFS

FORMERLY KNOWN AS THE CFIDS ASSOCIATION OF AMERICA

Welcome!
Our 1st Research Roundtable

Our Sincere Thanks

Massachusetts CFIDS/ME & FM Association

Education, Support and Advocacy since 1985



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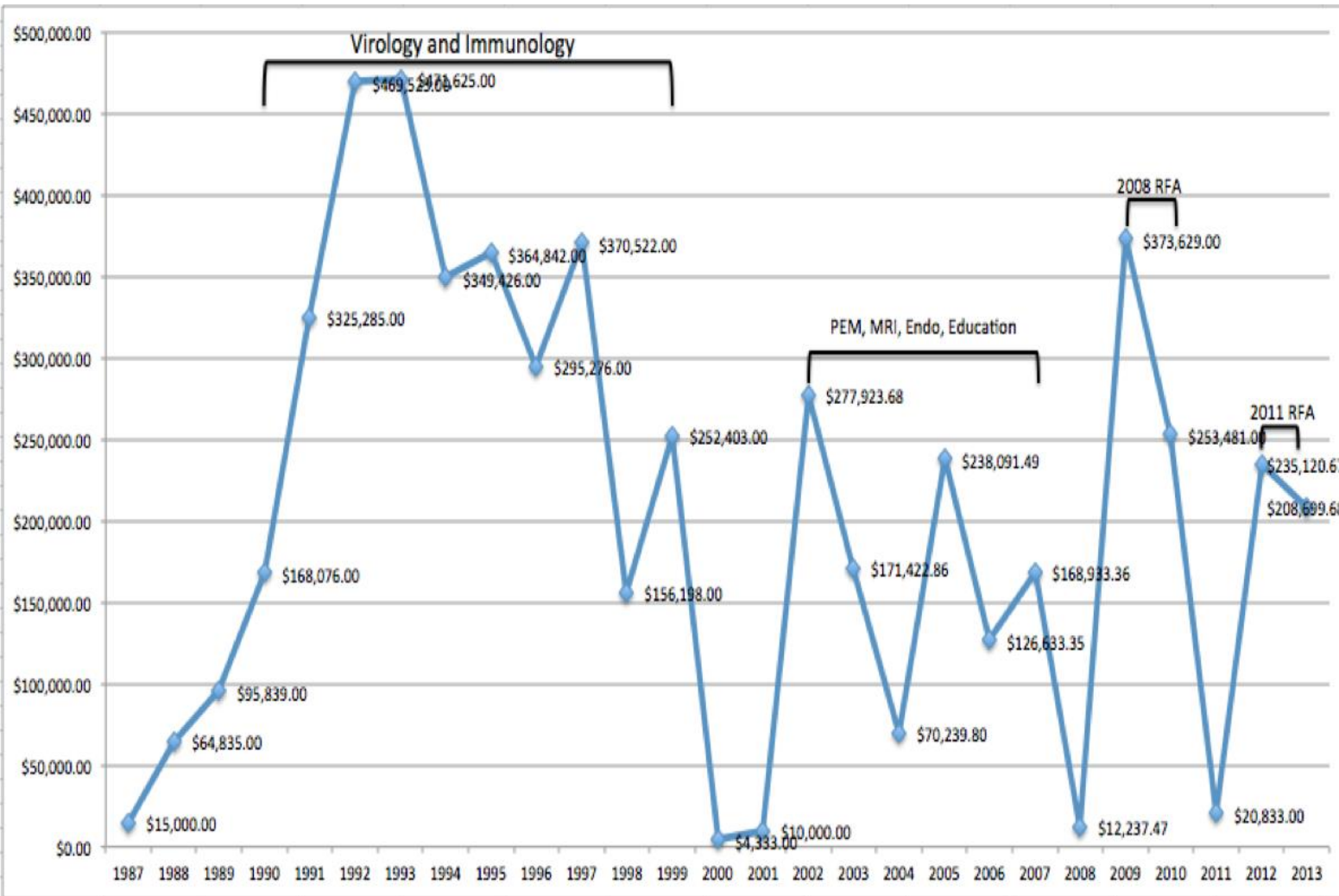
Our Mission:

Make ME/CFS understood, diagnosable and treatable.

Our Strategy:

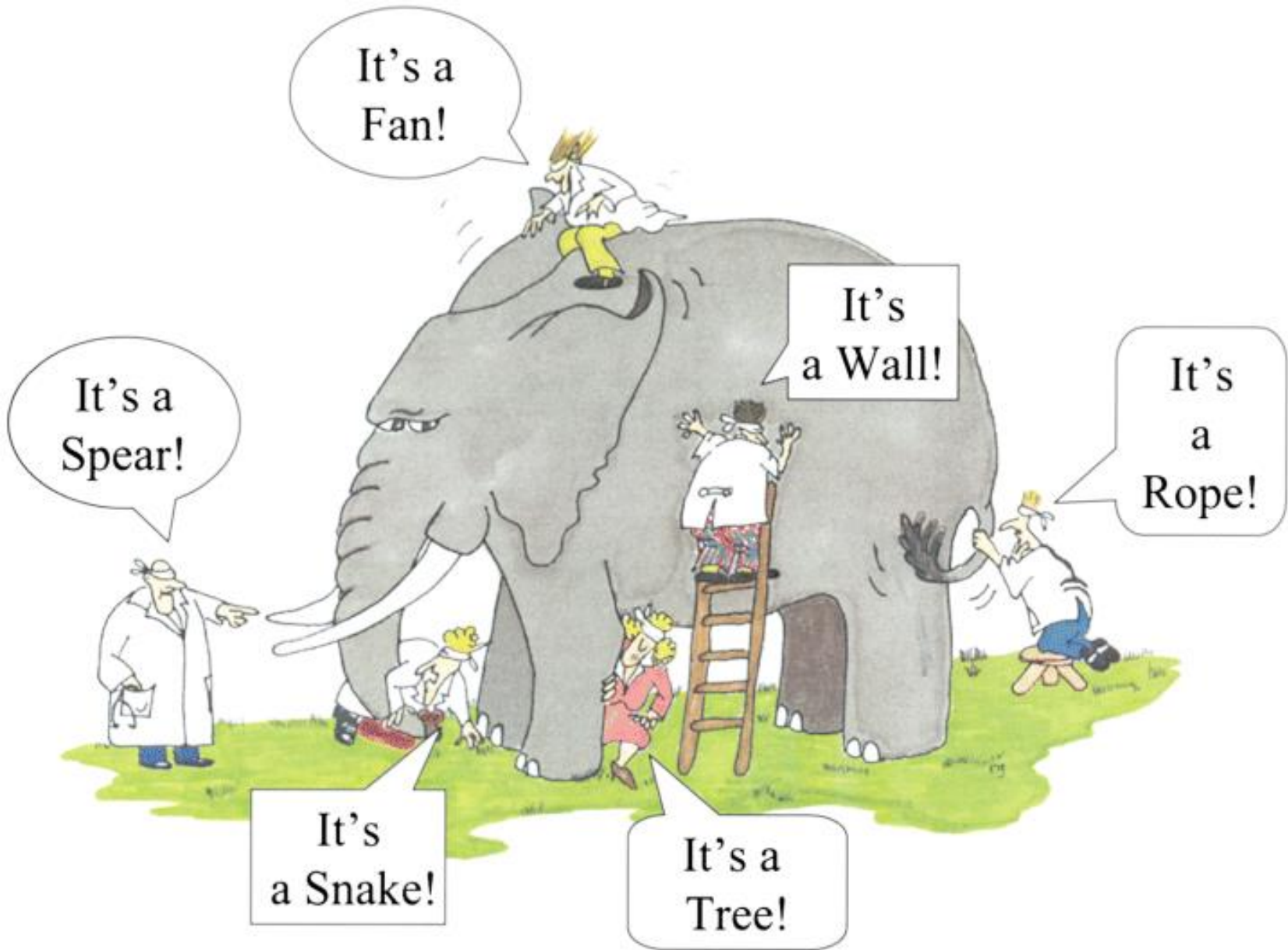
Stimulate participatory research aimed at the early detection, objective diagnosis and effective treatment of ME/CFS through expanded public, private and commercial investment

Largest and Most Successful Private Funder of ME/CFS Research



Cheney	\$670,905.00
Grossberg	\$651,496.00
Klimas	\$617,275.54
DeFreitas	\$411,967.00
Shungu*	\$235,603.00
Martin	\$231,200.00
Medow*	\$183,333.35
Schondorf	\$158,614.00
Suhadolnik	\$154,959.00
Huber	\$140,000.00
Snell/VaNes:	\$140,000.00
Knox	\$136,240.00
Broderick*	\$125,000.00
Shukla*	\$125,000.00
Rowe*	\$124,953.00
Biovista*	\$100,000.00
Cook*	\$100,000.00
Light*	\$100,000.00
Mishra*	\$100,000.00
Chazotte	\$98,506.00
Lebleu	\$97,000.00
McGowan*	\$89,750.00
Abbott	\$80,000.00
Friedman	\$79,996.00
Ding	\$77,262.00
Jacob	\$75,250.00
Papanicolaou	\$66,800.00
Ovadia	\$62,609.00
Glaser	\$61,187.47
Komaroff	\$52,500.00
Peterson	\$46,157.00
Bruno	\$36,811.00
Goldstein	\$34,810.00
Jason	\$31,569.00
Gunn	\$16,198.00
Bell	\$11,187.00
Preston	\$11,000.00
Levy	\$10,000.00
Buchwald	\$8,000.00



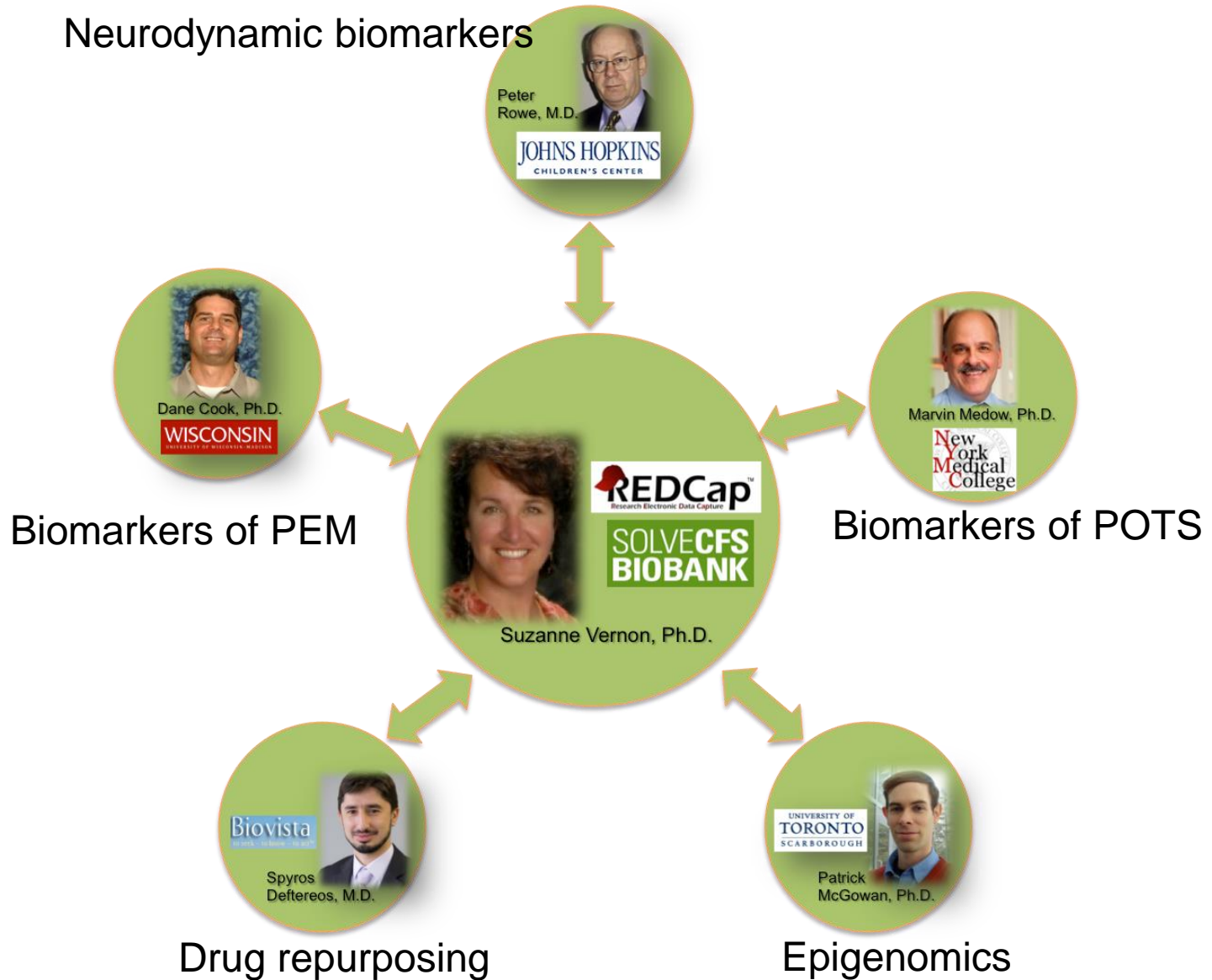


2008 – 1st ME/CFS Research Network

- **Successes**
 - Engaged new investigators and forged new collaborations
 - Projects were both hypothesis testing and hypothesis generating
 - Seed funded led to bigger funding – \$7.5 million
 - Several high impact collaborations
- **Lessons Learned**
 - Seed funding insufficient to make ME/CFS a focus of investigators research portfolio
 - Lack of access to well-characterized patients and samples
 - Lack of infrastructure to share and archive the data
 - Investigators move on



2011 – Discovery, Validation, Subtypes



Building the Resource Base

Generate

Antisense autoantibodies (value from GSK study)

Generate data samples in the SolveCFS BioBank
this resource to the research community and to help
researcher's action.

Immune Signatures

Antivirus fingerprint

Virome

Autoimmune Subtypes

Epigenomics

Drug Repurposing



Mike Cooperstock,
M.D.
University of Missouri



Michael Houghton, PhD
University of Alberta



Derya Unutmaz,
M.D.
NYU Medical Center



Steve Elledge,
Ph.D.
HHMI, Harvard



Armin Alaedini, PhD
Columbia University



Patrick McGowan, Ph.D.
University of Toronto



Spyros Deftereos, M.D.
Biovista

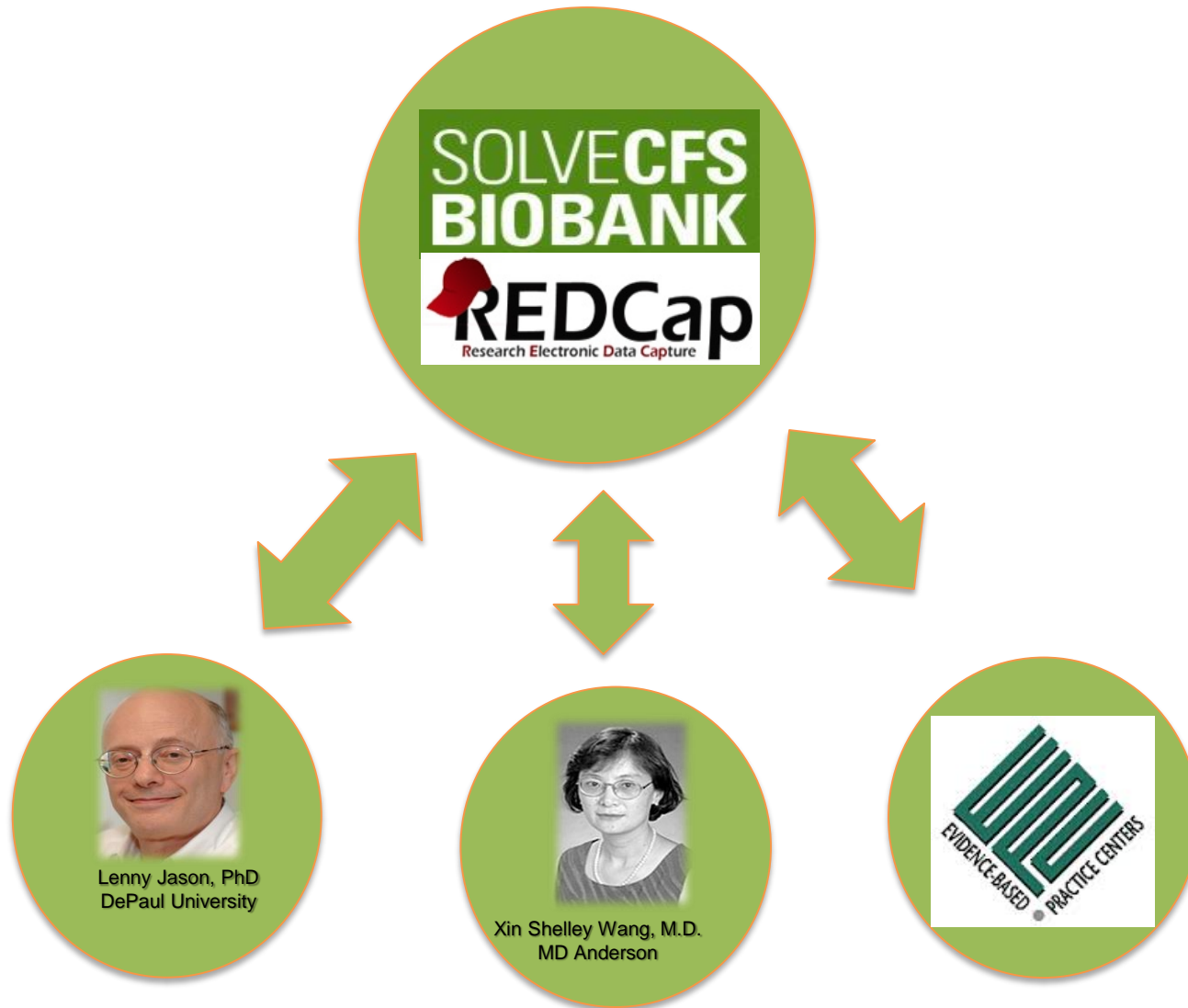


Eric Delwart, PhD,
UCSF, BSRI

**SOLVECFS
BIOBANK**



Self-Report Information



SolveCFS BioBank



SolveCFS BioBank – 2015 and Beyond

- Dr. Ralph & Marian Falk Medical Research Trust Catalyst Award - \$500,000 (11/14-11/15)
 - Objective of this is to expand epigenetics study and “restock” the SolveCFS BioBank
 - Dr. Lucinda Bateman – Clinical Investigator responsible for enrolling 300 participants: Collect clinical and survey information; blood
 - Dr. Patrick McGowan - epigenetics



Questions: New Criteria

- Will you be using the new SEID criteria in your research studies?
 - Clinical diagnostic criteria that is not operationalized for research, requires clinical intuition. But these diagnostic criteria help focus research
- What impact will these new criteria have on new research, and will studies using them be comparable to studies using Fukuda or CCC criteria?
 - Help guide research: boon for objective diagnostics – outcomes, devices
- Are there any particular areas of research that you are interested in sponsoring (e.g. areas noted in either P2P or IOM reports)?
 - Data from the SolveCFS BioBank was cited throughout the IOM report. FDA indicates the “core signs, symptoms and decrements of specific functioning” must be defined
- How do you ensure a diagnosis of ME/CFS is valid when asking for/collecting samples i.e. who determines diagnosis and how is this determined?
 - Current biosample inventory collected from 300 patients by Klimas, Peterson, Lapp and Bateman;
 - >1,200 participants in the SolveCFS Biobank, self-report diagnosis
 - 300 participants from current grant to restock
- Will this change with use of the new IOM clinical diagnostic criteria?
 - SolveCFS BioBank – “learning system”

Questions: Biology

- Vagus Nerve Infection theory by Dr. Michael VanElzaker
 - Important hypothesis that I agree with; challenges in testing
- If you can, please comment on the issue of children "inheriting" CFS from their parents. I breastfed and am also wondering if that might have put my 8 yr. old daughter
 - ME/CFS results from a combination of genetics (vulnerability) and the environment (exposures including infection)
- I am fairly sure of when I got CF FM. I had my first surgery wa slow loss of energy to follow. I am chem sensitive now. Some people claim chem. started their prob. Why are there so many diff. causes noted as offsetting of conditions?
 - Because these conditions are defined by non-specific symptoms like pain and fatigue. Must couple this important, clinically meaningful information with biological information – biomarkers (e.g., antibodies, cytokines, imaging)
- Has cord blood been considered in helping with the effects of Chronic Fatigue?

Why and What's Next

- For Dr. Vernon: Thank you for heading up SMCI's innovative and successful research program! You have announced you are leaving SMCI. Can you tell us why, and what are your next steps?
 - It has been a successful 7 years
 - Transformed \$1.2M in research funding to >\$12M
 - Lowered barriers to research with the SolveCFS BioBank
 - Attracted some of the brightest investigators from the best institutions into ME/CFS research
 - Return to research (and that includes ME/CFS)!
 - Continue to consult with SMCI, write the next grant
 - Stayed tuned





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