Many people with ME/CFS have become their own experts through independent research and sharing information with other patients and loved ones in the ME/CFS community. This patient-based knowledge has grown organically through online and in-person communities as a consequence of the knowledge gap and “expert desert” created by miniscule funding for ME/CFS. SMCI celebrates the patient experts and the exceptionally high engagement found in the ME/CFS community.

Ours is a disease community like no other.

Yet, the world of research is complex with its own language. To help decode and access the increasing work in science and discovery, we offer a collection of research terms and their application in the real-world, authored by our own Chief Scientific Officer and Vice President for Research, Dr. Zaher Nahle.

### BASIC RESEARCH:
A branch of scientific investigation, typically conducted in a laboratory, which involves specialized detection techniques, tools and methodologies. The aim is to uncover the communication, cross-talk (see definition below), structure or function within our cells, tissues, and organs, including the interactions between all these entities amongst each other as well as with the external environment. Basic science research can be done in both healthy and disease states. It is interdisciplinary and incorporates disciplines such as chemistry and physics, in addition to medicine. It is “basic” in that it is foundational, driven purely to understand a function, without a specific focus on clinical trials, therapies or cures.

### BIOENERGETICS:
The examination of the biological systems responsible for generating energy in any organism. The bulk of the energy production in a human cell that is needed for all functions, physical or cognitive, occurs in specialized structures inside the cells called mitochondria (singular: mitochondrion).

### BIOINFORMATICS:
a field of study that collects and extracts knowledge from complex biological data. Typically, it is computer-assisted and relies on modeling, algorithms (mathematical equations) and the processing of massive quantities of data (big data) and information to make sense of it all.

### BIOENGINEERING:
A field of study that applies biological principles to design and create new processes, products, or systems. It involves the use of engineering principles to solve problems related to the human body and health.

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### CO-MORBIDITY:
diseases or symptoms that occur simultaneously. (e.g. Fibromyalgia and ME/CFS are often co-morbid).

### CROSS-TALK:
instances in which one or more components of one molecular signaling pathway impacts another, affecting a common biological output. Can be characterized by mutual antagonism, co-regulation, or both positive and negative feedback loops. Cross-talk increases research complexity and difficulty in defining clear results.

### EPIDEMIOLOGY:
The study of the spread of diseases and other health-related factors or events and the application of this study to develop potential interventions.

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### GENETIC COUNTER:
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### GENETICS:
The study of our genes as organized with chromosomes, as well as genetic predispositions to disease or
Research ABCs (cont’d)

genetic variation, hereditary or familial associations or relationships between living organisms.

INSTITUTIONAL REVIEW BOARDS (IRB): entities that review, approve, and monitor research. IRB approval is necessary for human subject research.

ION CHANNELS: proteins in the membrane (outer wall) of a cell that allow ions (an atom or a molecule) to pass into or out of a cell. Ion channels are present in the membrane of all cells and control cell electrical signals, volume, and function.

METABOLIC DISEASE: the study of small metabolic products and related chemical processes of a biological system (organism, cell, or tissue).

MICROBIOME: a set of organisms that make up an ecological community, found in other organisms. The human microbiota includes bacteria, viruses, protozoa, fungi. These microbes are deeply integrated with our physiology and can impact health. For example, the “gut microbiome” is the collection of bacteria, viruses, protozoa and fungi found in the digestive tract.

NATURAL HISTORY (OF A DISEASE): a story or collection of facts about the course of a disease from its onset through its resolution (e.g., severity, onset, demographics, comorbidity). An Institute of Medicine report (Feb 2015) states that given the dearth in studies, especially those that are large in scale, it is hard to define the natural history of ME/CFS. This requires longitudinal study of large numbers of patients.

PEER-REVIEW: the evaluation of grants or proposals undertaken by experts with knowledge relevant to the field of study. The “gold-standard” of scientific rigor in making decisions regarding funding.

PERIPHERAL BLOOD MONONUCLEAR CELL (PBMC): any peripheral blood cell with a single, round nucleus. These populations of immune cells are collected from the peripheral (circulating) blood, and include lymphocytes, monocytes and dendritic cells. One track of ME/CFS research evaluates altered PBMC production of selected cytokines and immunoglobulins.

POST-EXERTIONAL MALAISE (PEM): the hallmark symptom of ME/CFS, PEM is profound fatigue following mental or physical exertion that is not alleviated by sufficient rest, which can impede daily functioning.

POSITRON-EMISSION TOPOGRAPHY (PET): a type of imaging scan that involves the injection of dyes with a radioactive tracer (molecules) that absorb into organs and tissues. In ME/CFS, PET scans have been used to explore the hypothesis that brain inflammation plays a role in the illness. There are many variations to this technology but with the same principles.

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS): a condition that impacts flow of blood through the body and results in an unusual increase in heart rate when someone stands up. The cluster of symptoms includes fatigue, dizziness and brain fog.

PREVALENCE STUDIES: Population studies to understand how many people have a disease, often done by geographic area.

REGISTRY: an organized system (database) that collects and stores uniform, detailed data to evaluate populations defined by a specific disease, condition or exposure. Individuals voluntarily provide information about themselves to these registries. Registries support research, including understanding the natural history of a disease.

TRANSLATIONAL RESEARCH: the application of basic research into practice for the benefit of humans. Within a medical context, the goal is to transfer knowledge from basic research to clinical application to improve health outcomes, i.e. treatments and cures.