



Alternative Therapies for Huntington's Disease



Kathleen M. Shannon, M.D.
Professor, Neurological Sciences, Rush Medical College
Director, HDSA Center of Excellence at Rush University Medical Center



Huntington's Disease Society of America

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2011 HDSA convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

Presenter Disclosures

Kathleen M. Shannon, M.D.

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

Huntington Study Group
Parkinson Study Group
National Institute of Neurological Diseases and Stroke
Michael J. Fox Foundation
Parkinson Disease Foundation
Cure HD Initiative



BACKGROUND

CAM Definition & Prevalence of Use

- a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine (AKA *Western* or *allopathic* medicine)
 - *complementary*: supplemental to conventional medicine
 - *alternative*: in place of conventional medicine
 - *integrative*: combination of conventional and scientifically supported CAM
- uUsed by 38% of adults in 2007 survey

NCCAM (<http://nccam.nih.gov/health/whatiscam>)



Biologically based approaches

Diets
Herbs
Vitamins



Manipulative and body-based therapies

Massage
Chiropractic
Osteopathy

Common CAM practices

Reiki
Magnets
Qigong

Energy therapies



Yoga
Spirituality
Relaxation

Mind-body interventions



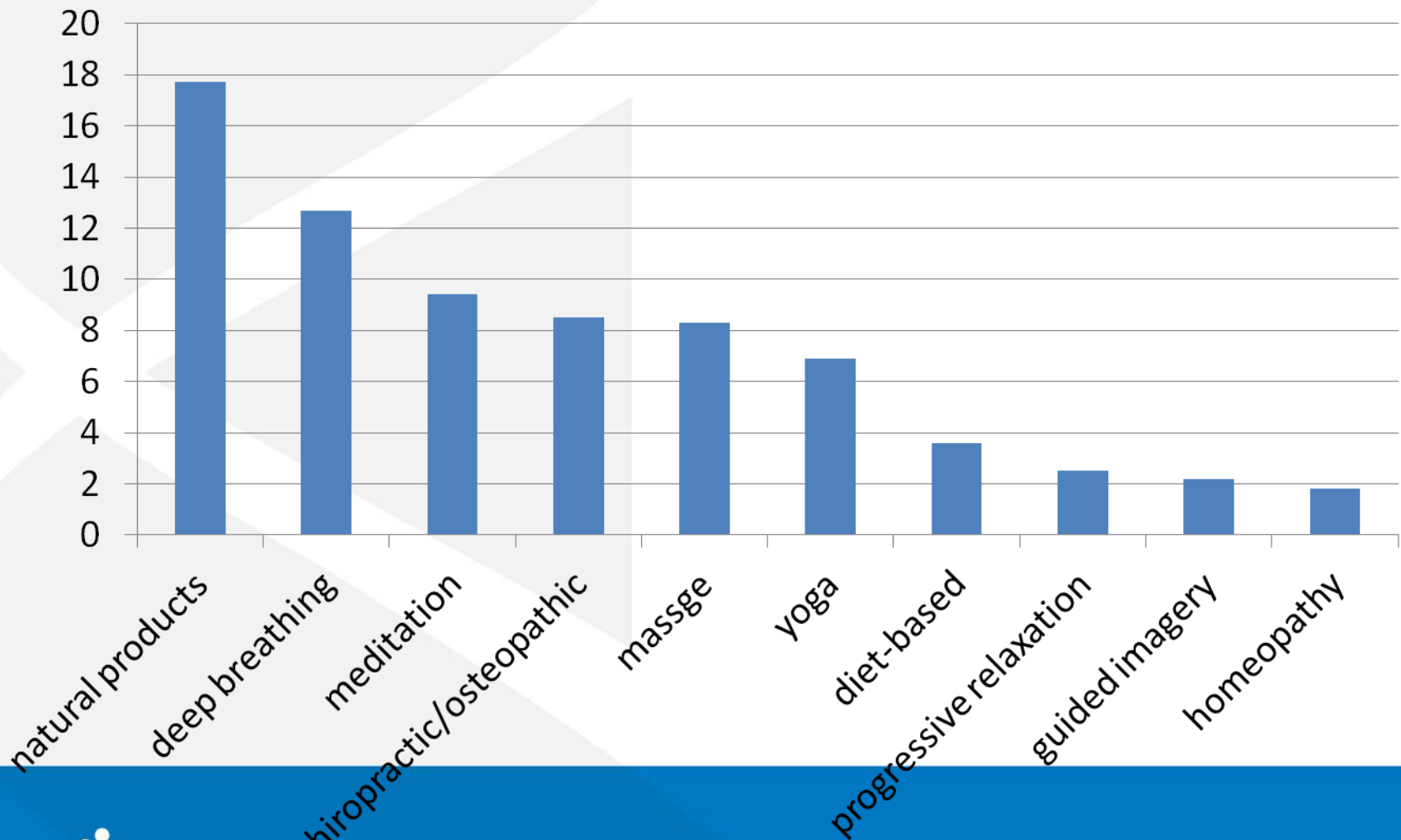
Homeopathy
Naturopathy
Ayurveda

Alternative medical systems



Nature Reviews | Immunology

Most popular CAM in US adults (38% adults, 12% children)



Types of CAM (1)

- natural products
 - herbal/botanical, vitamins, minerals, live microorganisms (17%)
 - most popular is fish oil
- mind and body medicine
 - meditation, yoga, acupuncture, deep-breathing, hypnotherapy, relaxation, tai chi, guided imagery (1.4-12.7%)

NCCAM (<http://nccam.nih.gov/health/whatiscam>)

Types of CAM (2)

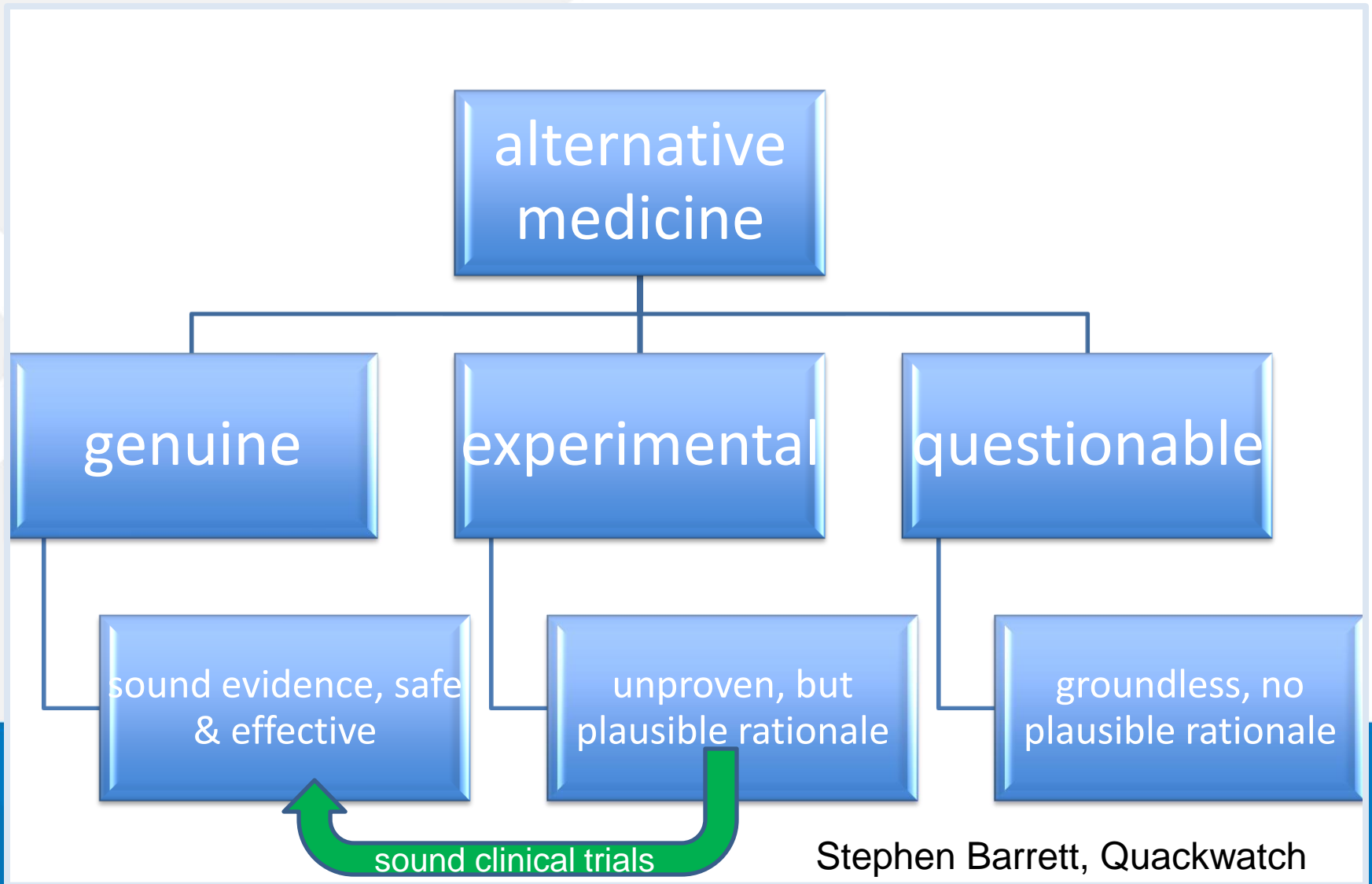
- manipulative and body-based practices
 - spinal manipulation, massage (8%)
- other
 - movement: Feldenkreis, Alexander, Pilates, Trager psychophysical integration (1.5%)
 - traditional healers (0.4%)
 - energy based: magnet, light, qi gong, healing touch (0.5%)
 - whole medical systems: Ayurvedic, traditional Chinese (1.8%)

NCCAM (<http://nccam.nih.gov/health/whatiscam>)

Common Characteristics of Alternative Therapies

- focus on individualizing treatments
- treating the whole person
- promoting self-care and self-healing
- focus on good nutrition
- preventive practices
- limited experimental and clinical study

Classification of alternative medicine



Stephen Barrett, Quackwatch

REGULATION OF NATURAL PRODUCTS

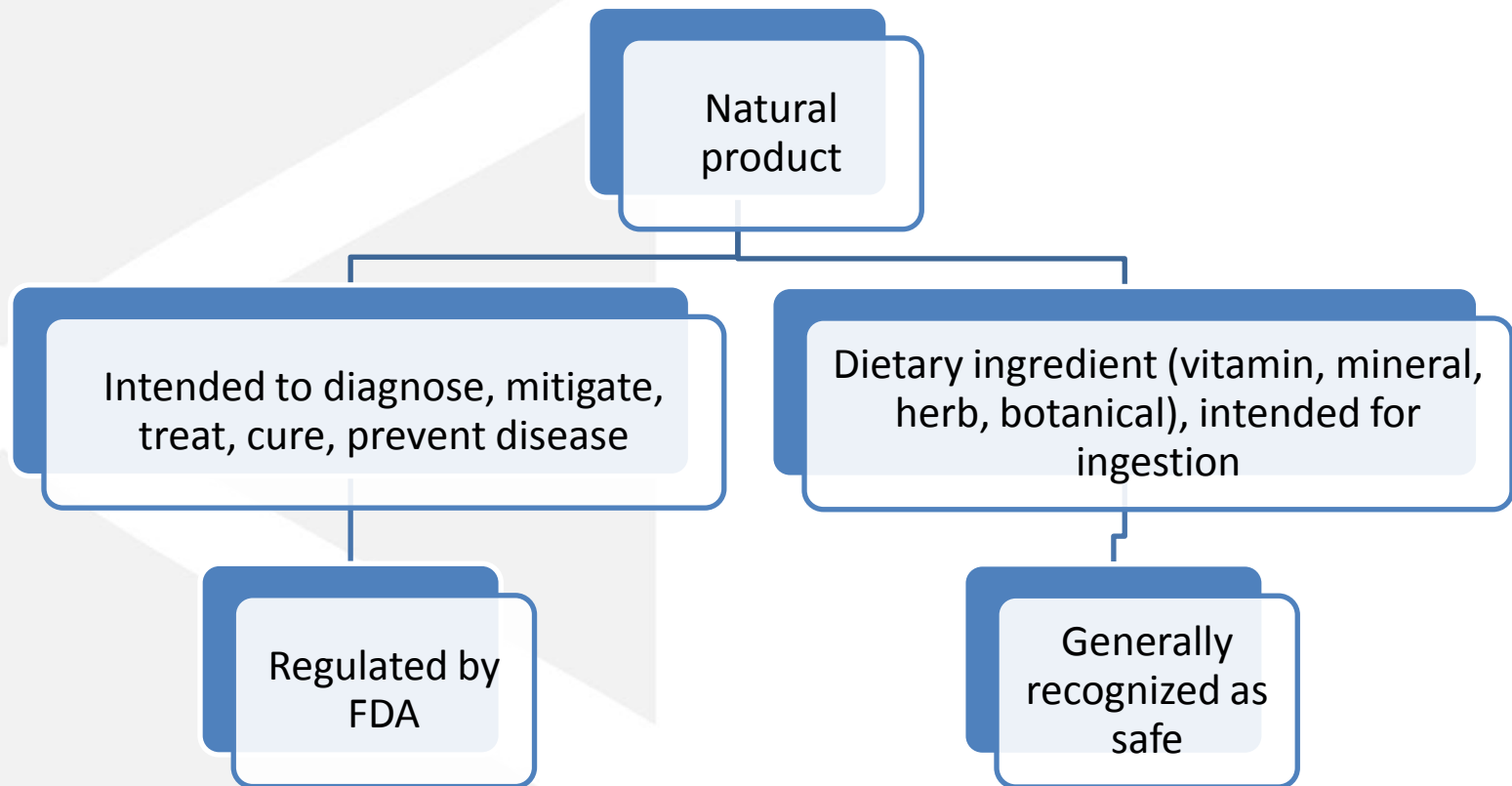
Government regulation

- manufacturers of dietary supplements are not required to provide safety & efficacy. FDA monitors safety and product information once on the market; and FTC monitors advertising
- no standardized system for credentialing CAM practitioners; some (chiropractic) require licensing in all states, but criteria may vary.

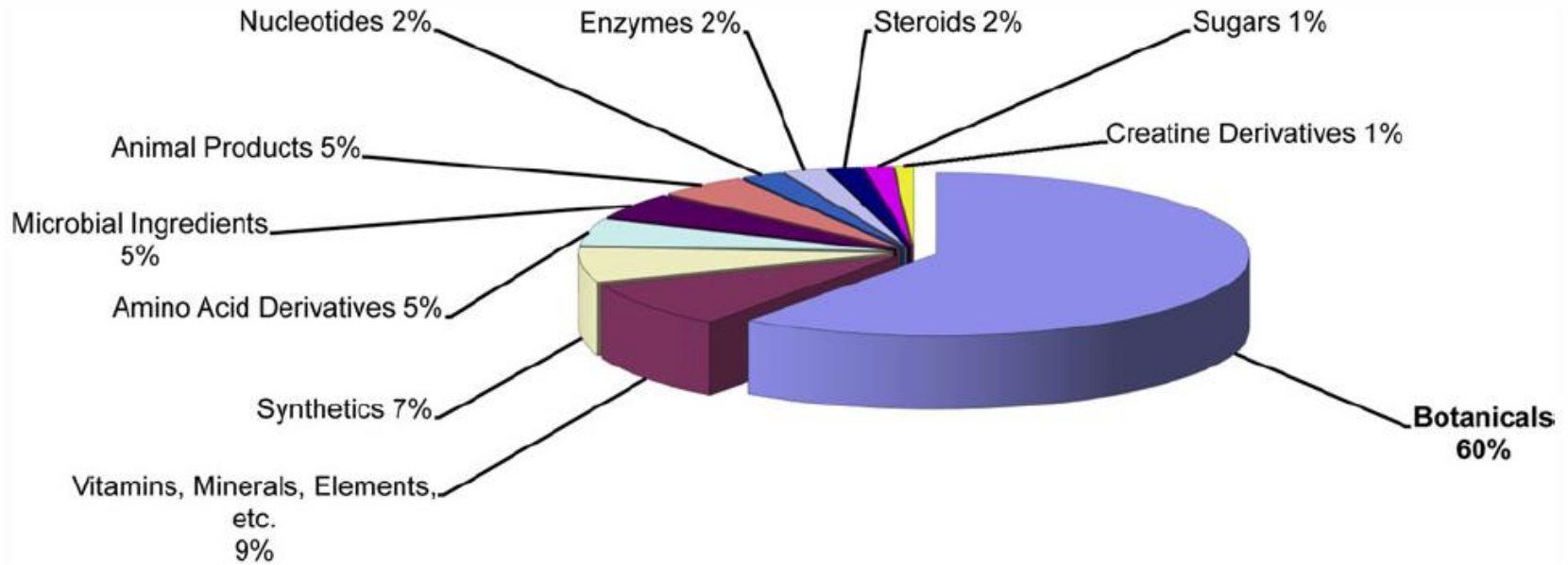
Regulation...

- pure Food and Drug Act (US) 1906
- internet has increased modern quackery
 - Americans waste \$27 billion/year on questionable health care, more than on medical research
 - “Practitioners use unscientific practices and deception on a public who, lacking complex health-care knowledge, must rely upon trustworthiness of providers” (Jarvis. 1992)

Regulation of natural products



Types of New Dietary Ingredients received by FDA



Abdel-Rahman et al. Toxicological Sciences 2011;123(2):333.

Assessing safety of natural products as NDI

- Establish identity
- General safety considerations (history of use, evidence of safety)
- Considerations for live microbial ingredients
 - # microbes
 - Properties of the microbe
 - Ability to persist in the gut
 - Resistance to antibiotics
- Reasons to exclude
 - Not a dietary supplement
 - Already authorized to study as a drug
 - Route of administration (e.g. not swallowed)
 - Needs toxicology testing

12 deadly natural treatments

- aconite
- bitter orange
- chaparral
- colloidal silver
- coltsfoot
- comfrey
- country mallow
- germanium
- greater celandine
- kava
- lobelia
- yohimbe



FROM NATURAL TREATMENT TO DRUG

SET-HD criteria

- scientific rationale
- kinetics & BBB penetration
- safety & tolerability
- efficacy
 - relevant animal models
 - human clinical studies



Potential compounds (SET-HD)

- amantadine
- ascorbic acid
- BN82451
- cannabinoids
- coenzyme Q10
- creatine
- cystamine
- cysteamine
- dichloroacetate
- ethyl-EPA
- geldanamycin
- HDAC inhibitors
- lipoic acid
- lithium
- minocycline
- mithramycin
- olanzapine
- OPC-14117
- paroxetine
- rapamycin
- remacemide
- tauroursodeoxycholic acid
- tetrabenazine
- trehalose

Potential compounds (SET-HD)

- amantadine
- ascorbic acid
- BN82451
- cannabinoids
- coenzyme Q10
- creatine
- cystamine
- cysteamine
- dichloroacetate
- ethyl-EPA
- geldanamycin
- HDAC inhibitors
- lipoic acid
- lithium
- minocycline
- mithramycin
- olanzapine
- OPC-14117
- paroxetine
- rapamycin
- remacemide
- tauroursodeoxycholic acid
- tetrabenazine
- trehalose

Studies of natural products & disease progression

Coenzyme Q10

- 347 subjects at 25 centers
- 120 weeks, double-blind, 4 arm study, CoQ10/remacemide
 - CoQ10 300-600 mg/day
 - Remacemide 400-600 mg/day
 - Both
 - Neither
- Negative study, “statistical trend” ($p=.13$)

******ongoing study: 2CARE******

Vitamin E

- 77 subjects at 1 center
- 52 weeks, double-blind, placebo controlled
- Negative study overall (? Some benefit in milder subjects)

Studies of natural products & disease progression

Ethyl-EPA

- 135 subjects, 6 centers
- 52 weeks, double blind, placebo controlled
- 2g/day
- Negative study

Idebenone

- 100 subjects, 1 center
- 52 weeks, double-blind, placebo controlled
- 270 mg/day
- Negative study

Studies of natural products & disease progression

creatine

- 42 subjects, 1 center
- 52 weeks, double-blind, placebo-controlled
- 5 g/day
- Negative study

****ongoing study: CREST-E****

A FEDERAL CENTER FOR STUDY OF CAM

National Center for Complementary
and Alternative Medicine

Third Strategic Plan
2011–2015

Exploring the Science of Complementary and Alternative Medicine

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
National Institutes of Health



NCCAM

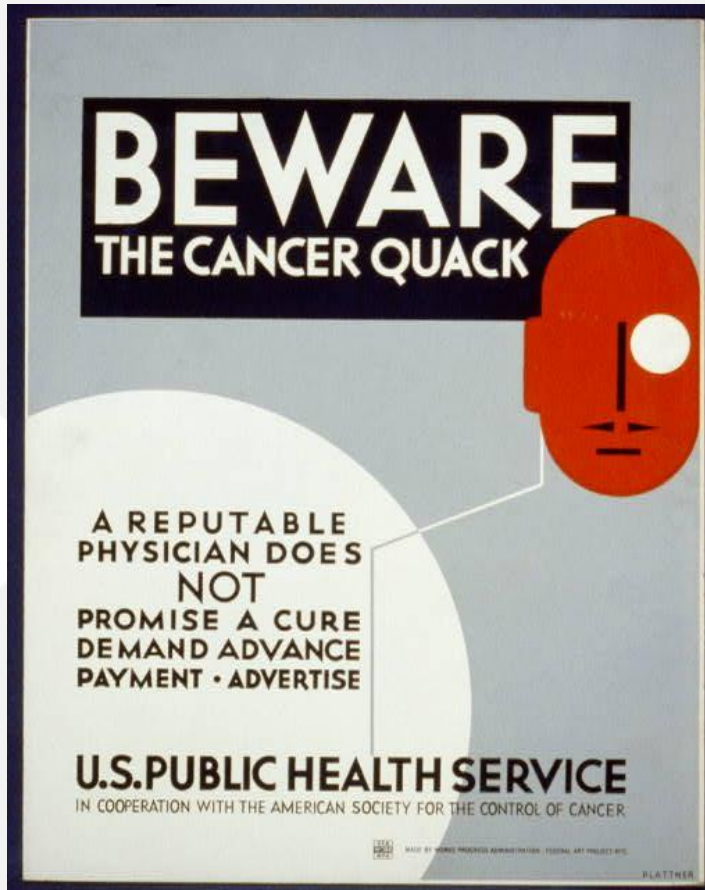
The mission of the National Center for Complementary and Alternative Medicine (NCCAM) is to define, through rigorous scientific investigation, the usefulness and safety of complementary and alternative medicine (CAM) interventions and their roles in improving health and health care. The Center's vision is that scientific evidence informs decision making by the public, by health care professionals, and by health policymakers regarding use and integration of CAM.

For more information....

- NCCAM Clearinghouse
 - 1.888.644.6226
 - TTY: 1.866.464.3615
 - nccam.nih.gov
 - info@nccam.nih.gov
 - Office of dietary supplements
 - ods.od.nih.gov
 - PubMed
 - www.ncbi.nlm.nih.gov/sites/entrez
 - NIH NLM Medline Plus
 - www.medlineplus.gov
- NCCAM (<http://nccam.nih.gov/health/whatiscam>)

ABOUT QUACKERY

Quackery



WPA poster, 1936-8

- “Quacksalver”
 - Hawker of salve
- Quackery ≠ fraud



Acceptance of quackery--reasons

- Ignorance
- placebo effect
- regression fallacy
- distrust of conventional medicine
- conspiracy theories
- fear of side effects
- cost
- desperation
- pride
- fraud

Notable quacks...

Franz Anton Mesmer	Magnetisme animal
Thomas Allinson	Naturopathy
Johanna Brandt	“Grape cure” for cancer
Samuel Hahnemann	Homeopathy founder
Lawrence Hamlin	Wizard oil cure for cancer
L. Ron Hubbard	Scientology
John Harvey Kellogg	Holistic methods
D.D. Palmer	Founder of chiropractic
Linus Pauling	Vitamin C cure for colds, cancer
Wilhelm Reich	Cloudbuster & Orgone Accumulator

25 ways to spot quacks and vitamin pushers

1. Only tell part of the story of nutrition
2. Claim most Americans are poorly nourished
3. Recommend “nutrition insurance”
4. Say most diseases have dietary causes & respond to supplements
5. Allege modern processing removes all nutrition from food
6. Claim diet is a major factor in behavior
7. Claim fluoridation is dangerous
8. Claim soil depletion and fertilizers result in less nourishing food
9. Claim ordinary food additives and preservatives are poisonous
10. Claim RDA’s have been set too low
11. Claim nutrition needs higher in stressed/diseased persons
12. Recommend health foods & supplements for everyone
13. Claim natural vitamins are better than synthetic

Barrett & Herbert. www.quackwatch.com

25 ways to spot quacks and vitamin pushers

14. Suggest questionnaire can diagnose need for supplements
15. Say it is easy to lose weight
16. Promise quick, dramatic, miraculous results
17. Routinely sell the products they recommend
18. Use disclaimers in pseudomedical jargon
19. Use anecdotes and testimonials
20. Claim sugar is a deadly poison
21. Display credentials not recognized by responsible scientists
22. Offer to determine nutritional state with lab test/questionnaire
23. Claim they are being persecuted by mainstream medicine
24. Warn you not to trust your doctor
25. Encourage patients to lend political support

Barrett & Herbert. www.quackwatch.com

“Cure” zone

- Diet
- Water cure
- Cleansing
 - Bowel, teeth, kidney, liver
- Physical activity
- Sweating
- Psychotherapy/spiritual therapy

“Cure” zone

- Abscess
- Acne
- Acid reflux
- Acidosis
- Addison’s disease
- Adrenoleukodystrophy
- Age spots
- Aging
- Aids
- Allergies
- Alopecia
- ALS
- Alzheimer’s disease
- Amenorrhea
- Anaphylaxis
- Anemia
- Anger
- Anxiety
- Arteriosclerosis
- Arthritis
- Asthma
- Athlete’s foot
- ADD
- autism
- Back pain
- Balance problems
- Blackheads
- Bladder cancer
- Bladder problems
- Blisters
- Body odor
- Bone cancer
- Bone spurs
- Bowel problems
- Brain cancer
- Brain injury
- Breast cancer
- Breast problems
- Bronchitis
- Bruising
- bursitis
- Cancer
- Cancer of the cervix
- Candida
- Cardiovascular disease
- Carpal tunnel
- Celiac disease
- Cellulite
- Cellulitis
- Chemotherapy side effects
- Chlamydia
- Cholesterol
- Chronic fatigue
- COPD
- Circulatory problems
- Cold sores
- Colic
- Colon cancer
- Common cold
- Constipation
- Cough
- Crohn’s disease
- Cystic acne
- Cystic fibrosis
- Cysts
- Dandruff
- Depression
- Dermatitis
- Dermatitis herpetiformis
- Diabetes
- Diarrhea
- Diverticulosis
- Drug addiction
- Dry skin

THERE ARE NATURAL LAWS & SCIENTIFIC PRINCIPLES

Homeopathy

- The only category of quackery legally marketable as drugs
- Products are made from minerals, botanical substances, etc.
- Dilutions: 1/1,000,000 to 1,000,000,000,000,000,000,000,000,000,000 (# > # H₂O drops that would fill a container > 50 times the earth's size)
- Oscilloccinum: freshly killed duck's liver and heart, incubated by 40 days, freeze dried, diluted and impregnated into surgar molecules ...

Principles of homeopathy

1. Law of similar
2. Law of simplex
3. Law of minimum dose
4. Theory of miasms
5. Doctrine of vital force
6. Potentisation/dynamisation
7. Hering's law of 5 directions of cure

WHAT TO DO?

Cautionary note

- Safety & effectiveness of many therapies is unknown
- Use precautions:
 - Select practitioners with care
 - Be aware of interactions between remedies and between CAM and conventional medications
 - Tell your physician about any remedies you are taking or practicing

Cautious guidance, informed action

- Avoid harm
- Avoid needless expense
- Take advantage of possible benefits
 - Probably won't hurt, but might help
 - Be aware of safe dose range
- Consider alternative choices
- Discuss with your doctor
- Revisit the decision
- Don't neglect mainstream treatments

QUESTIONS?