



# Alternative Therapies for Huntington's Disease



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Huntington's Disease  
Society of America

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# 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**



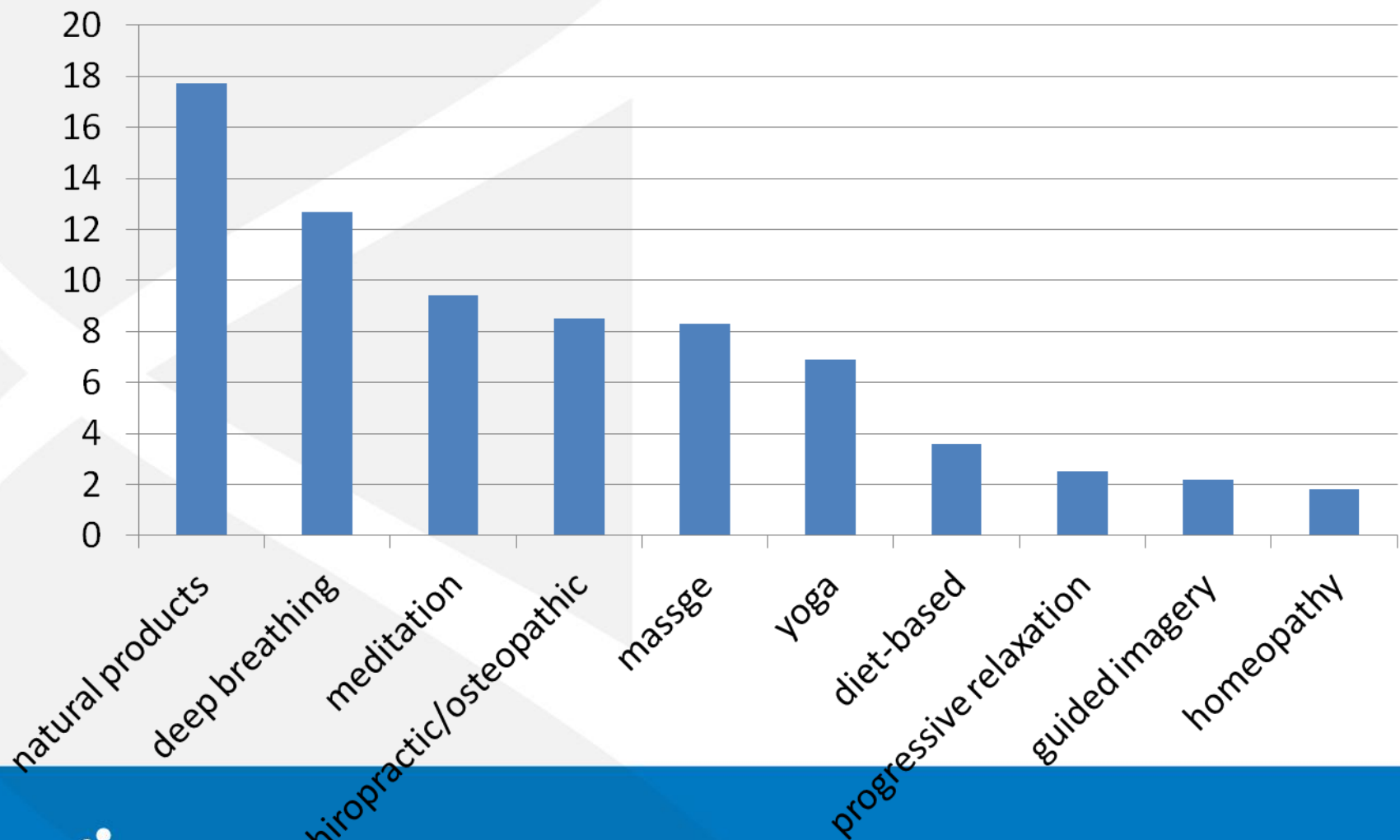
Homeopathy  
Naturopathy  
Ayurveda

**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)

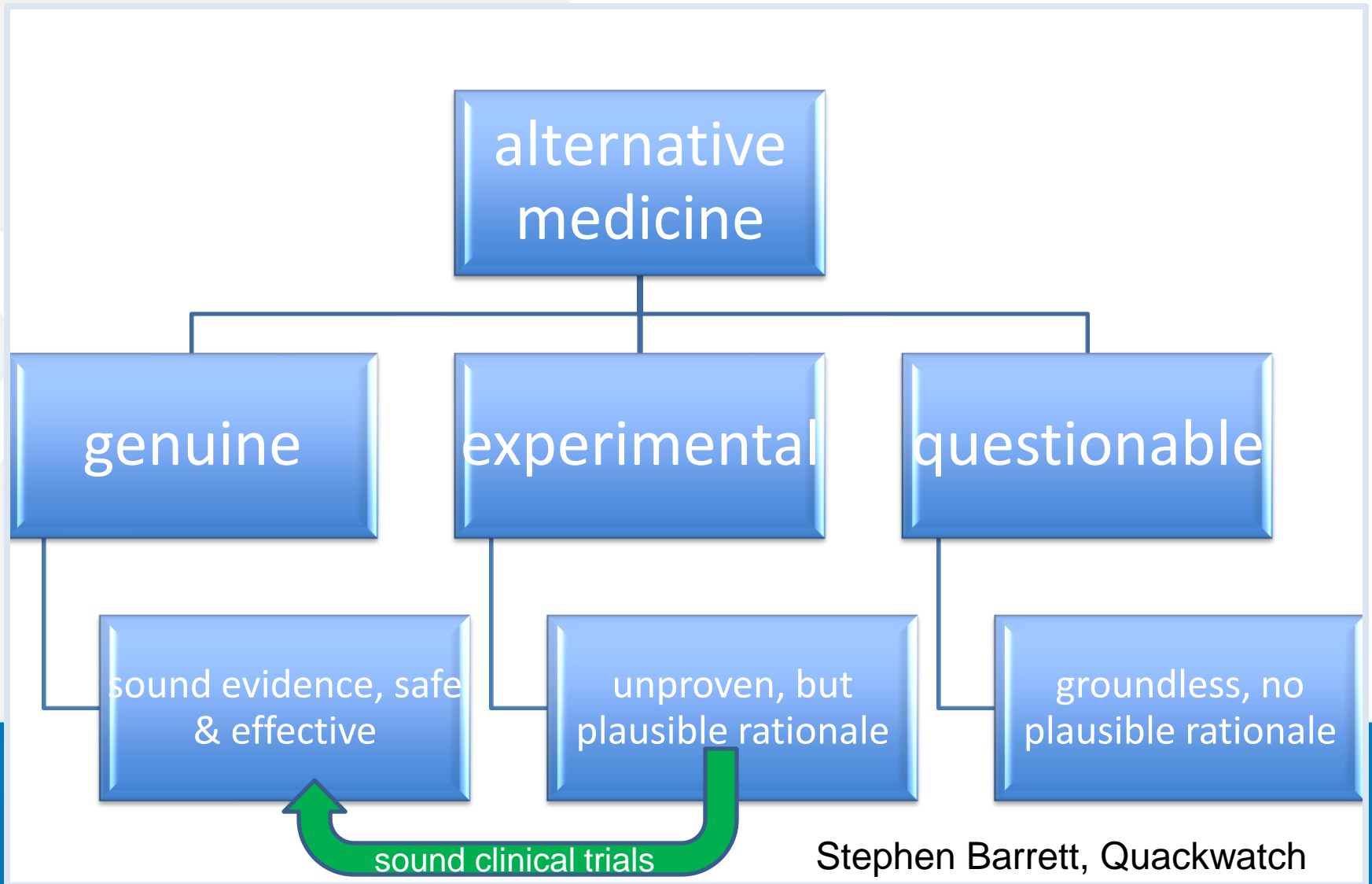
- manipulative and body-based practices
  - spinal manipulation, massage (8%)
- other
  - movement: Feldenkreis, Alexander, Pilates, Trager psychophysical integration (1.5%)
  - traditional healers (0.4%)
  - energy based: magnet, light, qi gong, healing touch (0.5%)
  - whole medical systems: Ayurvedic,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

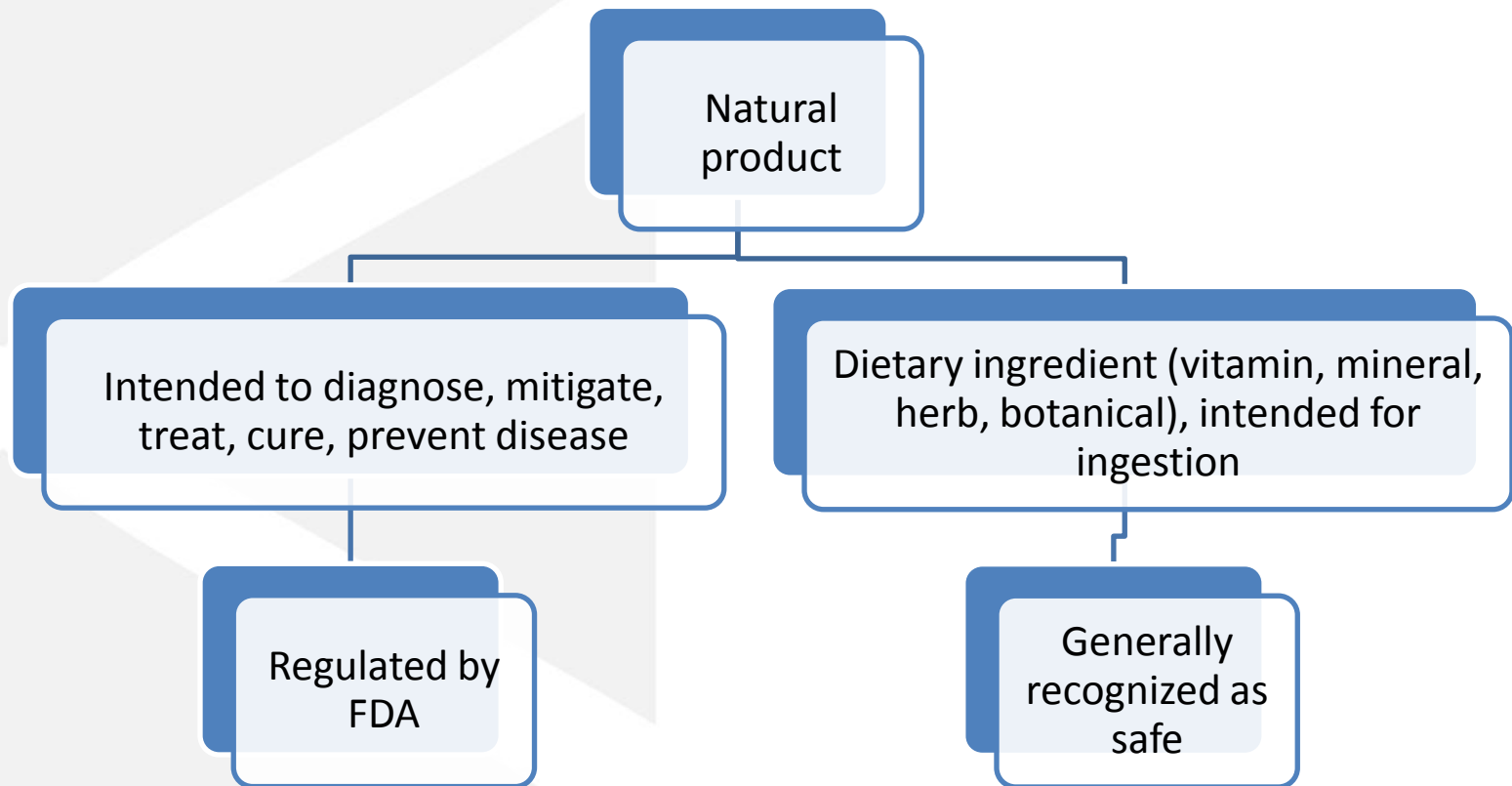
# Government regulation

- 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.

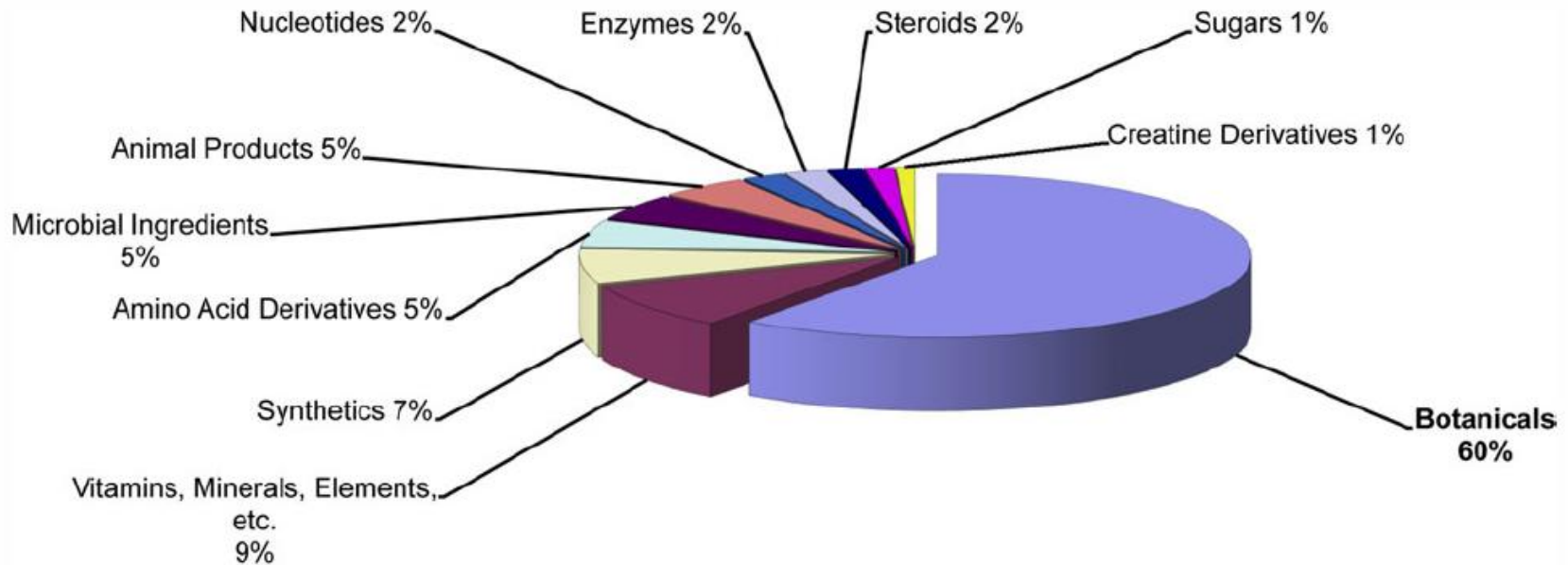
# Regulation...

- 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

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## 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

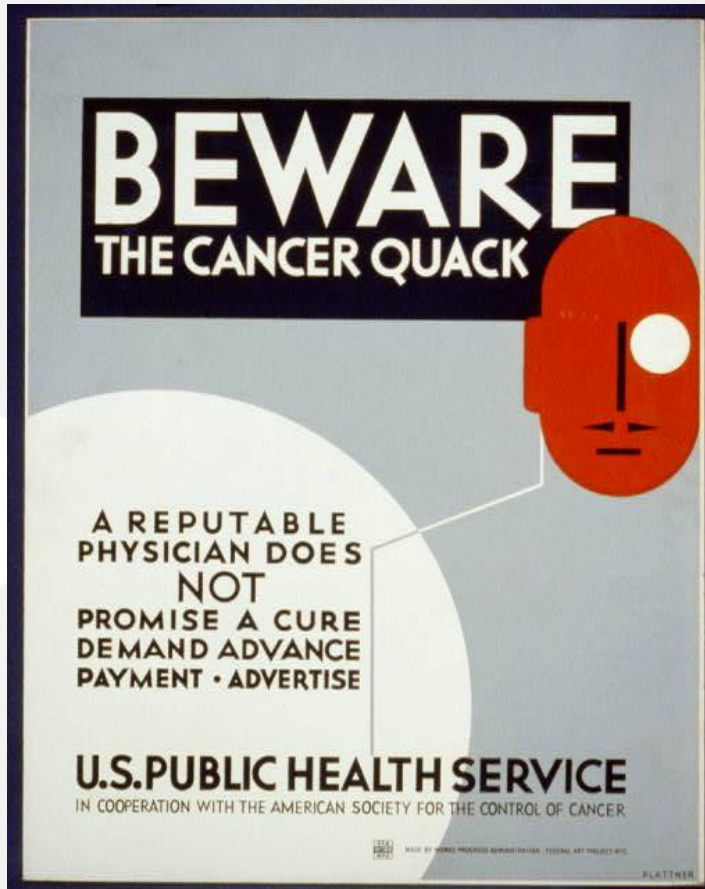
The mission of the National Center for Complementary and Alternative Medicine (NCCAM) is to define, through rigorous scientific investigation, the usefulness and safety of complementary and alternative medicine (CAM) interventions and their roles in improving health and health care. The Center's vision 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](http://nccam.nih.gov)
    - [info@nccam.nih.gov](mailto:info@nccam.nih.gov)
  - Office of dietary supplements
    - [ods.od.nih.gov](http://ods.od.nih.gov)
  - PubMed
    - [www.ncbi.nlm.nih.gov/sites/entrez](http://www.ncbi.nlm.nih.gov/sites/entrez)
  - NIH NLM Medline Plus
    - [www.medlineplus.gov](http://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](http://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](http://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 (# > # H<sub>2</sub>O 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?**