

CFSAC EDUCATION WORKGRP

- COMPLEX DISEASE REQUIRING EXPERT
- PREVALENCE UP TO 1 MILLION AMERICANS DEPENDING ON CASE DEFINITION
- OVER 452 MIL \$ & IN HEALTH CARE COSTS & 1.2 BIL \$ IN LOST PRODUCTIVITY

LITERATURE SEARCH

- MEDICAL STUDENTS ARE MORE LIKELY TO INCORPORATE INFORMATION ABOUT CFS/ME IN THEIR LEARNING SKILL SET
- NON-TRADITIONAL TEACHING FAVORED

PROFESSIONAL ORGANIZATIONS

- AMERICAN COLLEGE OF PHYSICIANS
- OUTDATED CASE DEFINITION
- INACCURACIES AND MISLEADING INFORMATION ABOUT TREATMENTS INCLUDING COGNITIVE THERAPY AND GRADED EXERCISE

AMERICAN BOARD OF N.P.'S

- MOST INVITING OF PROFESSIONAL ORGANIZATIONS
- USER FRIENDLY WEBSITE
- FACT SHEETS FOR BOTH PROVIDERS/PATIENTS
- OPEN TO ACCEPTING PRINT/INTERNET INFORMATION ABOUT CFS/ME AND ACCEPTANCE AT REGIONAL MEETINGS

AMERICAN BOARD OF FP

- MISINFORMATION IN PRINT ARTICLE
- WOULD CONSIDER (AFTER ONE OF OUR MEMBERS INVESTIGATED) ADDING CFS/ME TO TEACHING MODULES ONCE 'IMPORTANCE' AND 'RELEVANCE' OF ILLNESS WAS ESTABLISHED

ROLE OF NON-MD'S

- PHYSICAL AND OCCUPATIONAL THERAPISTS
- MORE HANDS ON APPROACH
- NOT ONLY HELP PATIENTS BUILD STRENGTH BUT TEACH HOW TO CONSERVE ENERGY FOR DAY TO DAY TASKS

PARTNERSHIPS AMONG MEDICAL PROFESSIONALS

- PHYSICIANS AND STUDENTS, NP'S, RN'S AND PA'S WORK TOGETHER AS A TEAM
- MORE MOTIVATION TO LEARN ABOUT CFS/ME BASED ON MY OWN RECENT EXPERIENCE
- CENTERS FOR EXCELLENCE MAY OFFER OPPORTUNITY IN CFS/ME FOR CLINICIANS AND RESEARCHERS TO SHARE INFORMATION

INTEGRATIVE MEDICINE PROGRAMS

- MORE WILLING TO INNOVATE TO IMPROVE OUTCOMES
- HAVE PERSONAL STAKE IN FACULTY/STUDENT DEVELOPMENT
- NON-WESTERN APPROACHES EMPHASIZED BUT NOT EXCLUSIONARY
- ONLINE VIDEOS AVAILABLE

WEB BASED OR VIRTUAL CARE OPTIONS/TELEMEDICINE

- ECHO CARE PROJECT IN NEW MEXICO UTILIZES TEAM OF EXPERTS WHO CONSULT WITH PRIMARY CARE DOCTORS IN RURAL AREAS ONCE WEEKLY
- CENTERS FOR EXCELLENCE COULD ACT AS RESOURCE FOR MEDICAL PROFESSIONALS IN UNDERSERVED AREAS

TELEMEDICINE CONT'D

- PATIENT CENTERED VIDEOS FEATURING INTERVIEW OF COMPLEX PATIENT FOLLOWED BY DISCUSSION; FEEDBACK SUGGESTED
- 14 STATES HAVE ADOPTED TELEMEDICINE AND OFFER 'NON-SYNCHRONIZED' CARE

SUPPORT GROUPS

- INTEGRAL AS A PATIENT RESOURCE
- ONES IN NJ, WISCONSIN AND MASSACHUSETTS WELL KNOWN FOR COMMITMENT TO EDUCATION, OFFER CME CREDITS, LIBRARY RESOURCE, SCHOLARSHIP FUNDS, ANNUAL CONFERENCE

OTHER ORGANIZATIONS

- CFIDS ASSOCIATION OF AMERICAN PARTNERS WITH OTHER AGENCIES; SUPPORTS PILOT RESEARCH
- IACFS: QUARTERLY NEWSLETTER; ANNUAL CONFERENCE FEATURING DISTINGUISHED SPEAKERS BUT VERY FLEXIBLE ABOUT NEW IDEAS; MAY FIND WAYS TO RECRUIT NEW MEMBERS; PANEL THIS YEAR ON MED ED

WEBSITES

- UP TO DATE AND OTHER APP'S DON'T PROVIDE LEVEL OF DETAIL NEEDED TO CONVEY COMPLEXITY OF CFS/ME
- MAY BE ABLE TO PARTNER WITH DRUG COMPANY OR ORGANIZATION TO PROVIDE INCENTIVE TO LEARN ABOUT CFS/ME

MEDICAL EDUCATION

- JASON 2013 ARTICLE SENT OUT SURVEYS TO US MEDICAL SCHOOLS ASSESSING RESEARCH/CLINICAL CARE IN CFS
- 50 % RESPONSE RATE; NOT CLEAR HOW ACCURATE SURVEY RESPONSES ARE SINCE THEY WERE SOLICITED BY RELATIVE OF CFS/ME PATIENT

MEDICAL EDUCATION CONT'D

- `HOME' FOR THIS DISEASE:
- GENERAL MEDICINE, I.D. ALLERGY, RHEUMATOLOGY
- INTRODUCTION DURING 1ST YEAR OF SCHOOL MORE TEXTBOOK LEARNING OR DURING CLINICAL YEARS
- OVERLAP WITH NEUROLOGY/CARDIOLOGY/GI

CDC WEBSITE

- CFSAC MEMBERS HAVE HAD NUMEROUS DISCUSSIONS ABOUT THIS
- RETURN TO PREVIOUS RECOMMENDATIONS
- SUBSTITUTE CCC DEFINITION FOR OUTDATED ONES
- BLACKBOX WARNING AGAINST PHYSICAL EXERTION

FINAL RECOMMENDATION

- THE WORKING GROUP ON EDUCATION FOR CFS/ME RECOMMENDS THAT HHS PROVIDE OPPORTUNITIES FOR DISSEMINATION OF INFORMATION THROUGH THE DEVELOPMENT OF A CURRICULUM AT ALL US BASED MEDICAL SCHOOLS PROVIDING THE TOOLS NEEDED FOR FUTURE PHYSICIANS TO RECOGNIZE CFS/ME AND TO MAKE APPROPRIATE REFERRALS;

FINAL RECOMMENDATION CONT'D

- WE SUGGEST THAT FUNDING BE ALLOTTED TO THE APPROPRIATE AGENCIES THAT CAN BEST DEVELOP TEACHING MODULES FEATURING CFS/ME PATIENTS WITH COMPLEX PRESENTATIONS
- WE RECOMMEND THAT HHS PARTNER WITH HRSA AND OTHER AGENCIES THAT SUPPORT INTEGRATIVE MEDICINE PROGRAMS FEATURING LEARNING ABOUT CFS/ME

FINAL RECOMMENDATIONS CONT'D

- WE SUGGEST THAT HHS ACT AS A RESOURCE FOR NOVEL PROGRAMS SUCH AS 'PROJECT ECHO' COMPRISED OF MULTIDISCIPLINARY TEAMS THAT REACH UNDERSERVED AREAS
- WE RECOMMEND THAT HHS ALSO PROVIDE SUPPORT TO GATHER REQUISITE DATA (PREVALENCE RATE/PHYSICIAN ATTITUDES) FOR ESTABLISHED ORGANIZATIONS, I.E. ABFP TO INCORPORATE CFS/ME INTO REQUIRED SELF ASSESSMENT MODULES

FINAL RECOMMENDATION

- WE ALSO RECOMMEND THAT HHS SUPPORT CFSAC'S EFFORTS TO AMEND CDC WEBSITE INFORMATION AS HAS BEEN DISCUSSED PREVIOUSLY
- FINALLY, WE HOPE THAT THE EFFORTS OF THIS WORKING GROUP WILL EXTEND BEYOND CFSAC AND FOSTER FURTHER IDEAS AND IMPLEMENTATION