

# Chronic obstructive pulmonary disease patient group succeeds on the internet: EFFORTS

Jean Rommes

EFFORTS Board of Directors, Kansas City, USA

*Correspondence to:* Jean Rommes, PhD. 9225 Cascade Avenue, Number 2313, W. Des Moines, IA 50266, USA. Email: jmrommes@edge-life.com.

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EFFORTS is a patient-run education, advocacy and support group with a webpage that gets hundreds of hits a day and a listserv of several thousand people, some of whom post daily on the main list or one of the sublists, and some of whom lurk. We are an international group with members from Europe and Africa as well as other parts of the world.

Started by a group of patients in the late 1990s, EFFORTS is highly regarded in the chronic obstructive pulmonary disease (COPD) world, especially in the US. EFFORTS has had representatives attend meetings such as the American Thoracic Society (ATS) and the American College of Chest Physicians (CHEST) annual conferences since 2000 and has had representation on groups such as the ATS Public Advisory Roundtable (PAR) Council. EFFORTS members also serve on the US COPD Coalition Board, local and state Lung Associations, Better Breathers groups and many serve on a variety of committees and boards through the COPD Foundation. Our members tend to be avid volunteers, and some serve as state advocates for the Foundation as well as representatives of the American Lung Association and other lung disease organizations. Certain of our EFFORTS community have been featured in local, national, and international newspaper and magazine articles, both online and in print, spreading awareness of the challenges of both patients and caregivers.

EFFORTS has partnered with the International COPD Coalition (ICC), the COPD Foundation, with the American Association of Respiratory Care and the American Association of Cardiovascular and Pulmonary Rehabilitation and representatives of EFFORTS attend both local and national meetings of those organizations. Representatives have also been invited to speak at international COPD conferences. EFFORTS also participates as much as possible in both local and national efforts to support (for positive) or actively discourage (for negative) legislation affecting people with lung disease and is

particularly good at getting members to write letters to their elected officials and has had representatives attend various “hill day” events where they have an opportunity to speak to their own legislators regarding issues involving lung health. EFFORTS members also have relationships with pharmaceutical and equipment manufacturing companies, serving on patient advisory groups and acting as patient advocates.

While we are always gathering new members, one of our difficulties is, of course, older members continue to age and in many cases, become more ill, and die. Constantly losing friends, people you've never met in person but come to know well online, is discouraging and sometimes depressing. Continuing to have members who can provide leadership and guidance in the management and maintenance of both the listserv and the website is difficult and we're constantly looking for new people to bring on board to help with both those aspects of EFFORTS.

Our primary position is that we're for anything that will help find a cure for COPD and all its related components. That drives most of the work that we do, the meetings our representatives attend and the education we provide our members, the medical community and the larger community.

We appreciate this opportunity to let the larger COPD community know who we are and what we do. Please visit us at our Subscriber Information Page (<http://emphysema.net/bbanner.asp>). We'd be delighted to have you join us!

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