

## CONGRESS SHOULD SUPPORT CFIDS FUNDING TRIPLE-TRACK APPROACH

	NIH RESEARCH REFORM		LEADERSHIP FROM DHHS	MAINTAIN CDC FUNDING
<b>YOUR "ASK"</b>	<p style="text-align: center;"><b>SHORT-TERM</b></p> <p>Write a letter* to NIH Director Elias Zerhouni and tell him to issue a "Request for Applications" (RFA) for CFS</p> <p>*Sample letter in packet.</p>	<p style="text-align: center;"><b>LONG-TERM</b></p> <p>Contact the Chair and Ranking Minority Leader of the House Commerce Committee or Senate HELP Committee and ask them to support creation of an office of trans-NIH initiatives.</p> <p>*Fact sheet in packet.</p>	<p>Sign on to a letter* to HHS Secretary Leavitt that seeks immediate implementation of 11 recommendations from The Chronic Fatigue Syndrome Advisory Committee (CFSAC).</p> <p>*Sign-on letter in packet</p>	<p>Contact the Chair and Ranking Minority Leader of the Labor/HHS Appropriations Subcommittee and tell them to increase the Centers for Disease Control and Prevention (CDC) FY06 baseline to the current level of funding (\$8.9 million).</p> <p>* Funding chart in packet</p>
<b>POINTS TO MAKE</b>	<p>Despite the fact that the NIH budget doubled between 1999-2004, CFS research declined. Today, funding for CFS research stands at just \$4 million a year.</p> <p>The NIH budget office overstated CFS research funding 20% by including studies that even the lead researchers said had nothing to do with CFS.</p> <p>NIH has ignored the direction of the Appropriations Committees to expand its CFS research program.</p> <p>In June 2003, NIH's Dr. Vivian Pinn made a formal commitment to issue a Request for Applications (RFA) that emphasizes multi-disciplinary studies of CFS. That commitment remains unfulfilled.</p>	<p>In July 2003, the Institute of Medicine expressed its support for increasing trans-NIH strategic planning and funding.</p> <p>Congressional leadership has identified several priorities for NIH reauthorization, including a plan to expand the Office of the Director's authority to allow funding transfers between institutes to improve trans-NIH collaborations.</p> <p>The Office of the Director should establish an Office of Trans-NIH Initiatives to oversee these collaborations. This office would provide the structural and financial support needed to guide, track and help generate positive outcomes from trans-NIH initiatives of all kinds.</p>	<p>The Chronic Fatigue Syndrome Advisory Committee (CFSAC) to the Department of Health and Human Services has met quarterly since September of 2003.</p> <p>The CFSAC issued a series of 11 recommendations to the Secretary for Health on August 23, 2004, including: establishing 5 Centers for Excellence, issuing a \$10 million RFA for CFS and developing an international network of collaborators for CFS.</p> <p>The Secretary has yet to act on these recommendations.</p>	<p>From 1995-1998, \$12.9 million earmarked for CFS research was diverted to other programs. Pressure from CFS advocates and Congress resulted in restoration of the full \$12.9 million from 2000-2005.</p> <p>CDC is running the most comprehensive CFS program in the U.S.</p> <p>CDC supports education of primary care providers and public awareness programs.</p> <p>At the end of this fiscal year (FY05), all the payback funds will be exhausted.</p>