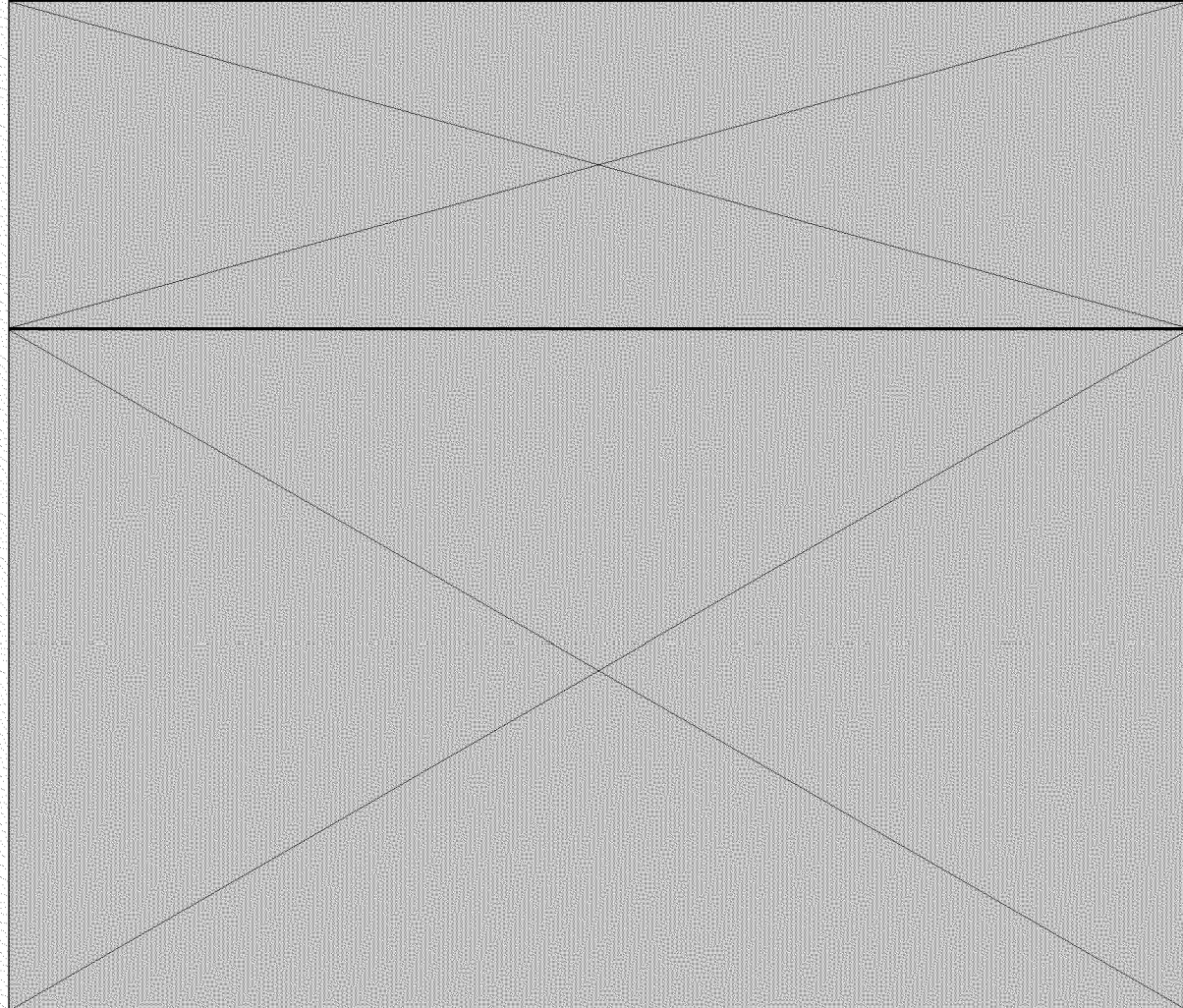


To: Hupp, Millan[hupp.millan@epa.gov]
From: SMCI This Week
Sent: Tue 9/12/2017 10:14:04 PM
Subject: SMCI This Week | Victories and publicity from coast to coast

This weekly update for the ME/CFS community includes media and partnership announcements, upcoming events and national policy victories for ME/CFS nationwide. [Email not displaying correctly? View it in your browser.](#)



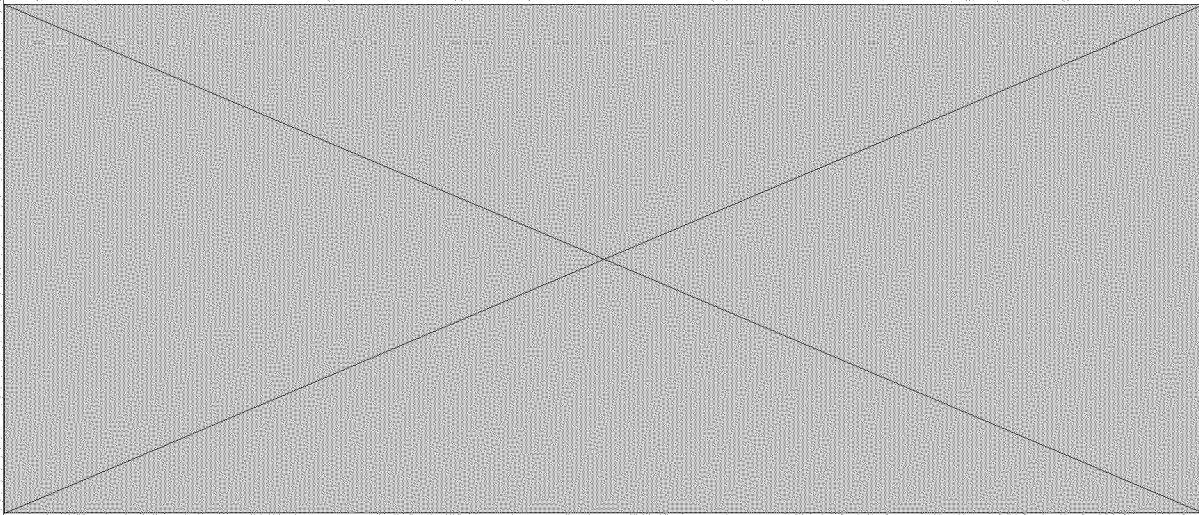
Did you see ME/CFS on PBS last week?

In 2015, Tom Camenzind appeared to have it all. He was an accomplished sophomore at Stanford University. But one day, things went horribly wrong. His health deteriorated rapidly and the diagnosis was heartbreaking: he had ME/CFS.

Today, Tom cannot speak. He is frozen in time, bedridden and unable to stand light, sound or touch. But if there is one tiny silver lining, it is that the world is about to learn of his plight – shedding light on this disease well beyond our ME/CFS community. Severely ill patients like Tom cannot speak for themselves; we are determined to speak to the world for them.

A national, televised program on Tom's plight aired last week on the show, "The White House Chronicle," with host Llewellyn King. Watch this new, half-hour program includes

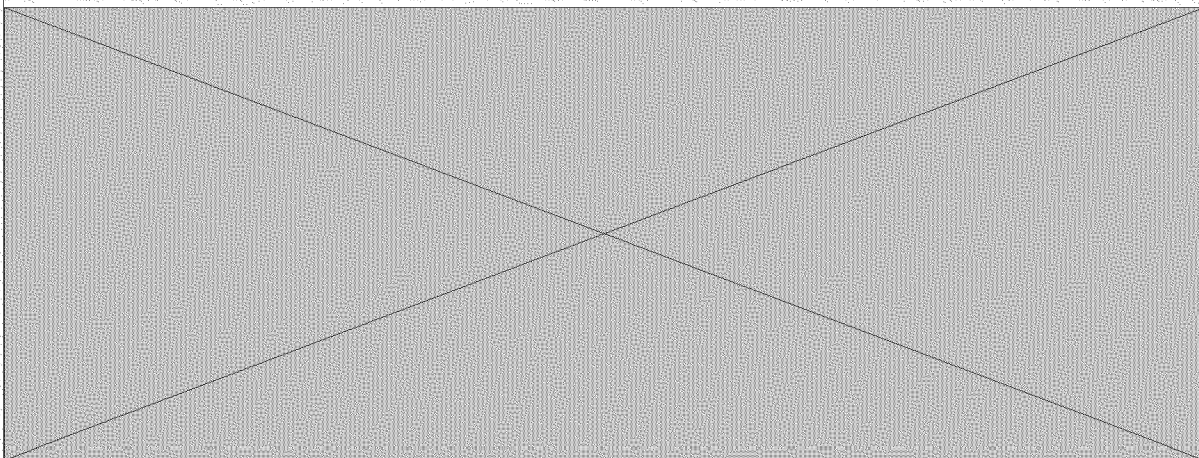
heartrending interviews with Tom's parents and powerful comments from SMCI President Carol Head.



Pictured above: Longtime ME/CFS Advocate Courtney Miller and SMCI Director of Advocacy and Public Relations Emily Taylor hold a copy of the NV delegation letter

First of its kind! Nevada delegation sends letter to NIH on ME/CFS

On September 8th, Nevada's full Congressional Delegation sent a letter to Director Collins of the National Institutes of Health urging him to "strengthen and accelerate" its work on ME/CFS! The letter was led by Representative Amodei from Reno and signed by Senators Catherine Cortez Masto and Dean Heller, and Representatives Jackie Rosen, Ruben Kihuen and Dina Titus. We are so pleased to have teamed up with Courtney and Bob Miller, Anita Patton and people with ME/CFS across Nevada to bring the very first ME/CFS delegation letter. Thank you to the many residents of Nevada who took action to make this possible. View the complete letter [here](#).



Pictured above: Simmaron Board chairman Jan Armstrong and SMCI Director of Advocacy and Public Relations Emily Taylor

Simmaron Research Institute Hosts Patient Day

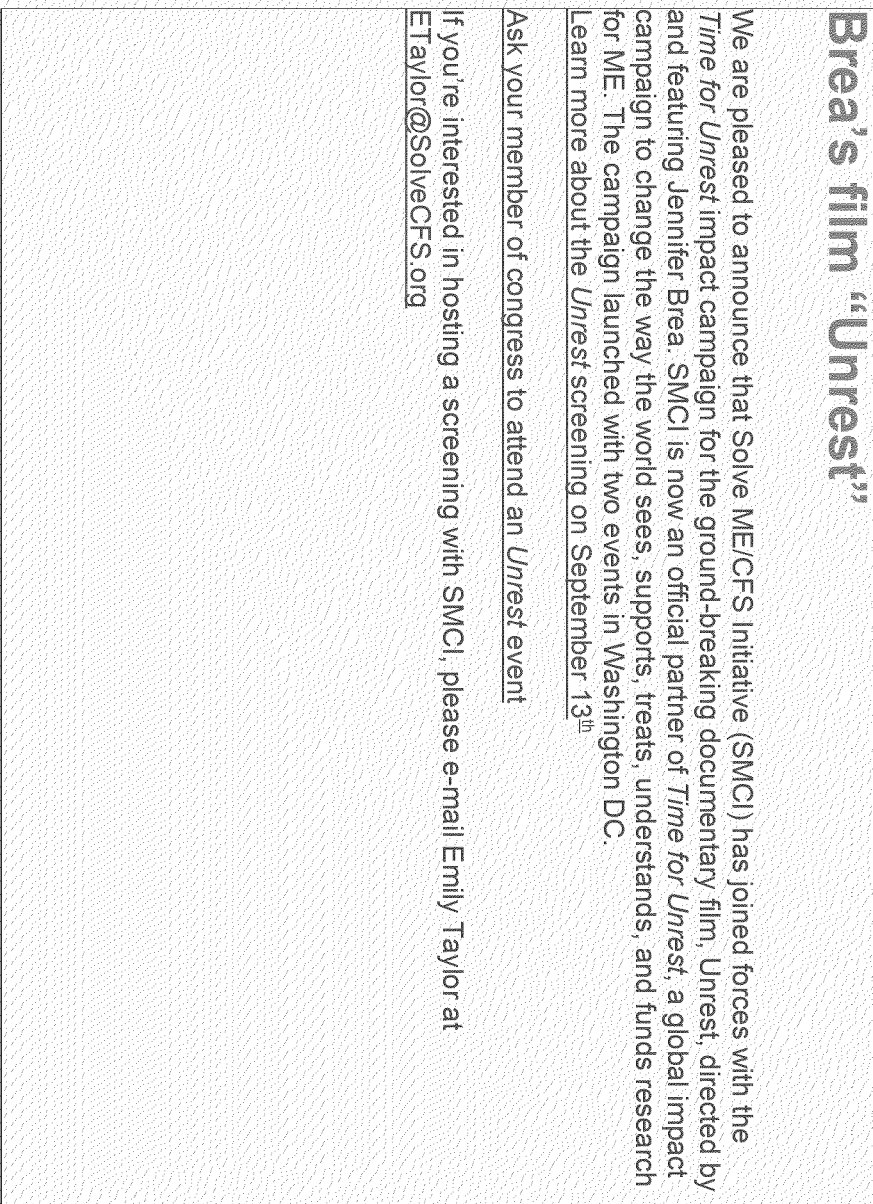
Brea's film "Unrest"

We are pleased to announce that Solve ME/CFS Initiative (SMCI) has joined forces with the *Time for Unrest* impact campaign for the ground-breaking documentary film, *Unrest*, directed by and featuring Jennifer Brea. SMCI is now an official partner of *Time for Unrest*, a global impact campaign to change the way the world sees, supports, treats, understands, and funds research for ME. The campaign launched with two events in Washington DC.

[Learn more about the Unrest screening on September 13th](#)

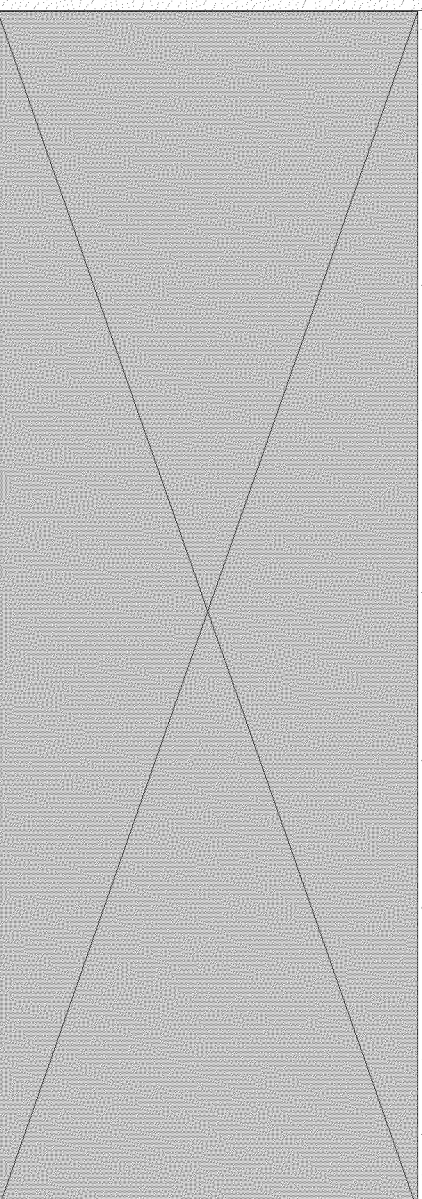
[Ask your member of congress to attend an Unrest event](#)

If you're interested in hosting a screening with SMCI, please e-mail Emily Taylor at ETaylor@SolveCFS.org

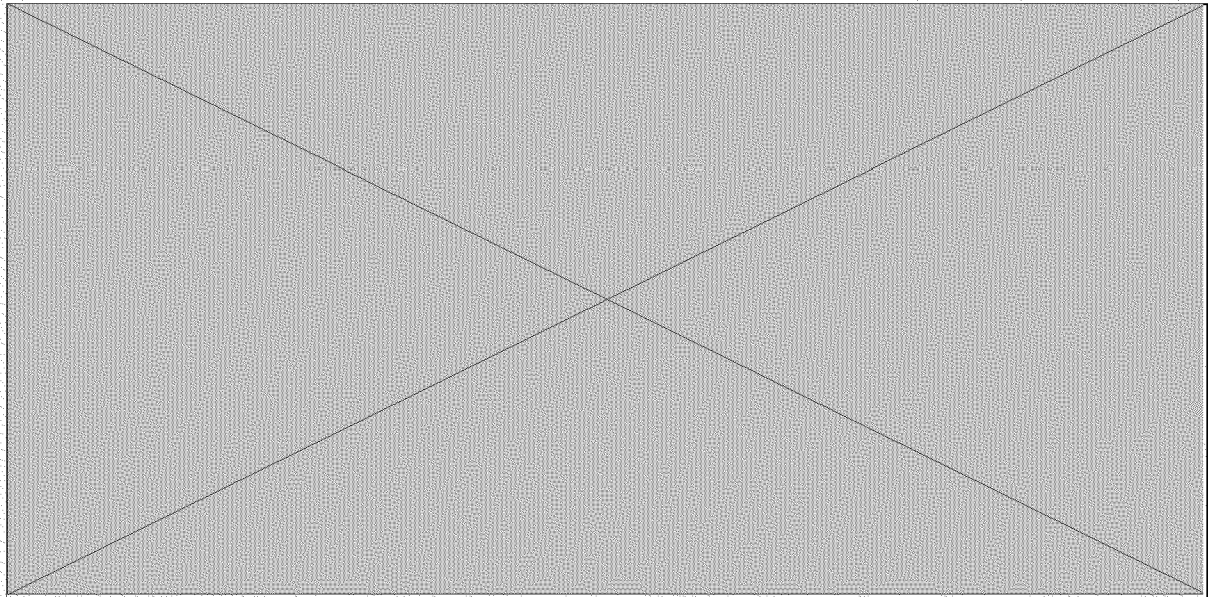


Research Update

On September 9th, the Sirmaron Research Institute (SRI) hosted its annual Patient Day and Research Update in Incline Village, Nevada. The program featured remarks from SRI's partner researchers, clinical care team and staff. Dr. Maureen Hanson of SMCI's Research Advisory Council presented a summary of her recent work including data from the partnership with SMCI and data obtained from an NIH R21 grant. A full summary of the event will be included in next week's e-newsletter. Research 1st.

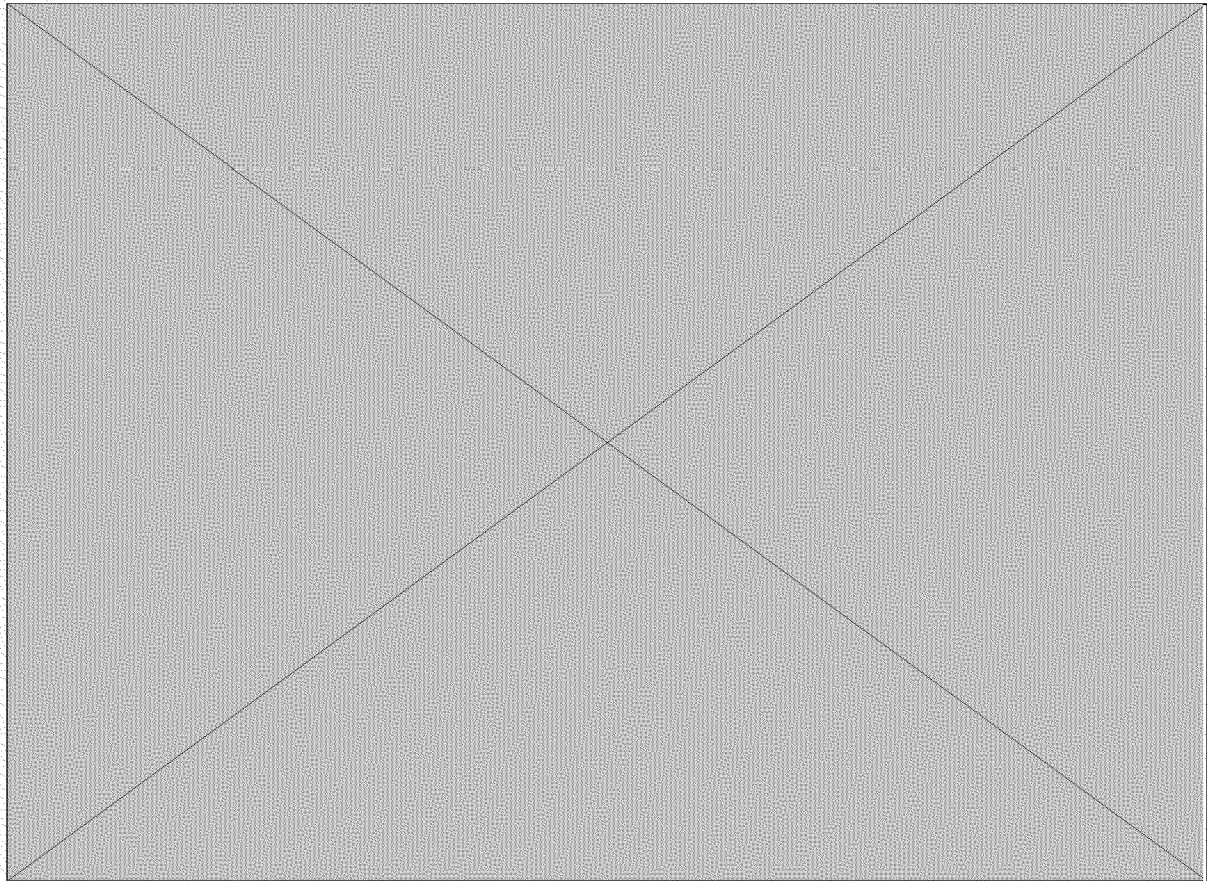


Solve ME/CFS Initiative partners with Jennifer



SMCI national tour makes first stop in Minnesota

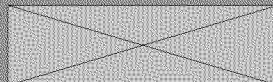
Minnesota Board members, Steve Curry and Sue Perpich, are hosting two seminal events on ME/CFS in Bloomington, MN. The public is invited to two receptions in Minnesota on September 28th with SMCI President Carol Head and Chief Scientific Officer and Vice President for Research Dr. Zaher Nahle for a discussion about ME/CFS. This event is part of a national tour describing the progress and success of SMCI's programs and research. If you are interested in attending, please contact Diana Sagini at 704-364-0016 ext. 208, or by e-mail at dsagini@solvecfs.org



Senate Appropriations Committee recommends restoring ME/CFS funding

On September 7, the ME/CFS community breathed a sigh a relief as the Senate Appropriations Committee passed S. 1711 with accompanying committee report language that recommends restoring the \$5.4 million chronic fatigue syndrome program under the CDC's National Center for Emerging and Zoonotic Diseases. In July, the House version of the budget (H.R. 3358) had zeroed out these funds in the House Committee report. Both the House and Senate reports include several recommendations to CDC, NIH, and HHS that were proposed by SMCI, #MEAction, and other advocates during the May ME/CFS Advocacy Week. We are pleased to see this support and growth of interest reflected in the Senate appropriations bills and look forward to continuing to fight for these items to be included after the reconciliation process in the final budget legislation in October.

The work of SMCI is entirely fueled by gifts large and small from people just like you.



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