

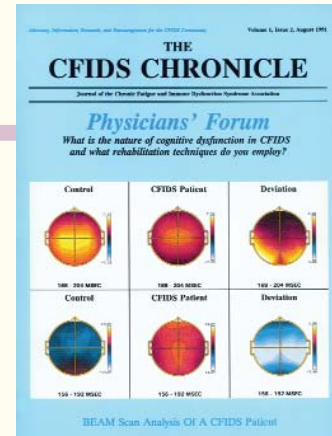
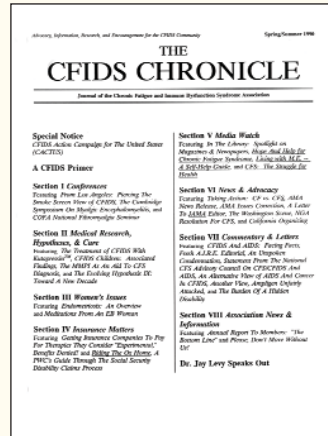
The *CFIDS Chronicle*: The Life Line of a Lifeline

“The Chronicle. It’s my lifeline.”

If the CFIDS Association got a dollar every time that exact statement has been expressed over the past 22 years, we could fund another research project or two.

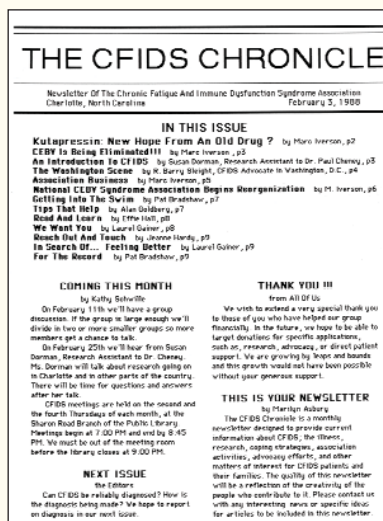
Begun as a monthly newsletter to keep the Charlotte-area CEBV Support Group informed about meetings, group activities, research and other support functions around the country, the *CFIDS Chronicle* has evolved since 1987 to be the world’s premier source of information about CFS/CFIDS/ME. It has taken many forms over the years, and its content has shifted as the needs of the community have changed and as other publications have come and gone.

Now it’s time again to reinvent the *Chronicle*. Though future plans still aren’t set, it seems a fitting time to look back and honor this publication that has served so many people so well for so long.

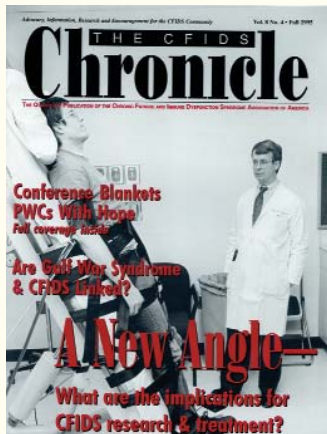


As research efforts expanded from a handful of clinicians to include university-based researchers, the *Chronicle* served as a clearinghouse for hypotheses and preliminary study data. Physicians treating CFS patients offered clinical insights and reported on promising treatments. The spring/summer 1990 *Chronicle* was the heaviest by weight and the most text-heavy of all the issues to date. Its 188 pages included not one photo, no graphics and very little white space.

An effort to bring more regularity to the publishing schedule reduced the size of each *Chronicle* and by 1992 it was mailed on a fairly reliable quarterly schedule. We also added a new format called *A Physicians' Forum* that provided several doctors' answers to a single question such as “How do you diagnose CFS?”



In the early days of the Association, the *Chronicle* was started as little more than a local support group newsletter. It gained wider readership through the guest columns written by pioneering clinicians including David Bell, MD, Paul Cheney, MD, PhD, Dan Peterson, MD, and Jay Goldstein, MD. Support group leaders from around the country shared their groups' news in its pages, giving readers a more diverse set of perspectives from people like Jan Montgomery (then of San Francisco), Lynda Dooley (Rhode Island) and Marcia Wheat (Texas). Editorial pieces collected from writers around the country championed activism and engagement. The voices of Dennis Jackson, Craig Barshinger, Jerry Crum and Barry Sleight helped shape early advocacy efforts.



Improved publishing software helped us give the *Chronicle* more of a magazine “feel” by the mid-1990s. Color, photos and graphics became less expensive to use in the publication and allowed us to tell stories from the CFS community with a more personal approach. Circulation reached its peak of 18,000+ in fall of 1995 with an issue focused on the important link established by Johns Hopkins University researchers between autonomic nervous system dysfunction and CFS.

By the end of the 1990s the Association was becoming more involved in efforts to educate health care professionals about CFS, and the *Chronicle* spun off some of its clinical and research content to a separate print publication titled the *CFS Research Review*. During this time, Association members were invited to submit the names of two health care professionals to receive the new publication free-of-charge. Members themselves received both publications. The *Research Review* was also sent to medical professionals we met through any of our subsequent training activities. The *Research Review* was published until 2007 when education funding shortfalls made the separate publication too costly to continue.

Three special publications and 13 annual reports round out the Association’s major publishing record over the years. All were intended to inform, educate and inspire those inside and outside the CFS community. The first, *Snapshots of CFIDS*, sent to members in 2000, captured the photos and stories of seven patients dealing with different aspects of the CFS experience. In 2005, we compiled a special double-issue *Chronicle* featuring CFS research findings and directions. Then in 2008 *Defining Moments: 20 Years of Making CFS History* recognized the Association’s 20 years of service and charted the people, events and topics that shaped the first two decades of the CFS community.



Currently the 32-page *Chronicle* features a blend of treatment, research, regular departments and personal stories. But readership has fallen off, as more people make use of online education and information resources. Rising costs for producing and mailing such a substantive print publication on a quarterly basis force us to evaluate our publishing strategy. Our firm commitment to maintain high quality communications vehicles and to value the diversity of readers’ needs will guide decisions. New solutions will attempt to balance print publications with electronic formats, hard news with human interest features. Your input is welcome and we look forward to sharing the next evolution with you.

The Association also publishes the monthly *CFIDSLink* e-news bulletin. Start your free subscription now at www.cfids.org/archives/cfidslink.asp