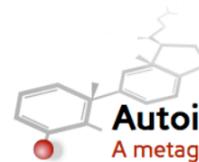


Web 2.0 Offers New Opportunities for Patient Care and Research

Paul Albert, Weill Cornell Medical College, New York, NY, U.S.A.



Weill Cornell Medical College

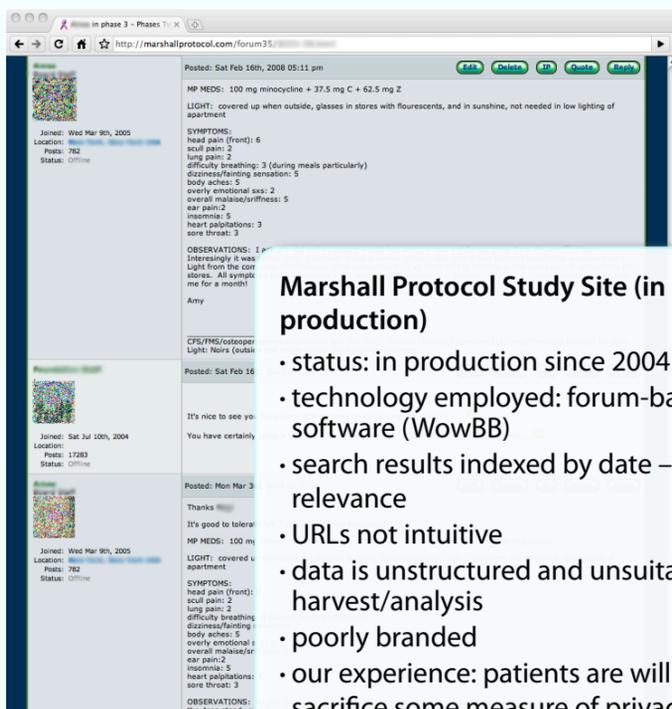


Autoimmunity Research Foundation
A metagenomic understanding of chronic disease

ABSTRACT: In 2004, Autoimmunity Research Foundation was founded with the purpose of studying a promising treatment for sarcoidosis and several other chronic inflammatory diseases known as the Marshall Protocol. Patients on the Marshall Protocol work with a prescribing physician to take pulsed doses of antibiotics and regular doses of olmesartan, a medication which activates the immune response. Many, though certainly not all, patients report their progress at MarshallProtocol.com, an online forum which compliments rather than supersedes regular visits to the doctor. Thanks to the Foundation's advisory resource, Knowledge Base, located at mpkb.org, doctors are able to ensure their patients have clear expectations about the treatment. Further, patients have reported that the online forums offer them a chance to compare their symptoms to others and to gain emotional support, which increases

adherence to treatment guidelines. This site is useful to doctors themselves, who review self-reported case histories, ask medical questions of one another in doctors-only forums, and monitor their patients. Another group served by the MP site are those of us associated with the Foundation intent upon further developing the Protocol. Feedback from patients has allowed us to conclude that the immunopathological reaction among autoimmune patients administered this treatment is near universal. Also, web-based feedback has allowed us to fine tune ambiguous treatment instructions for patients, many of whom suffer from cognitive dysfunction. Among web-based forums for patients to report on treatment progress, MarshallProtocol.com is not alone. If subject pool contamination bias is not a consideration, online forums offer a novel and useful way to improve upon a therapeutic approach.

Progress Reports

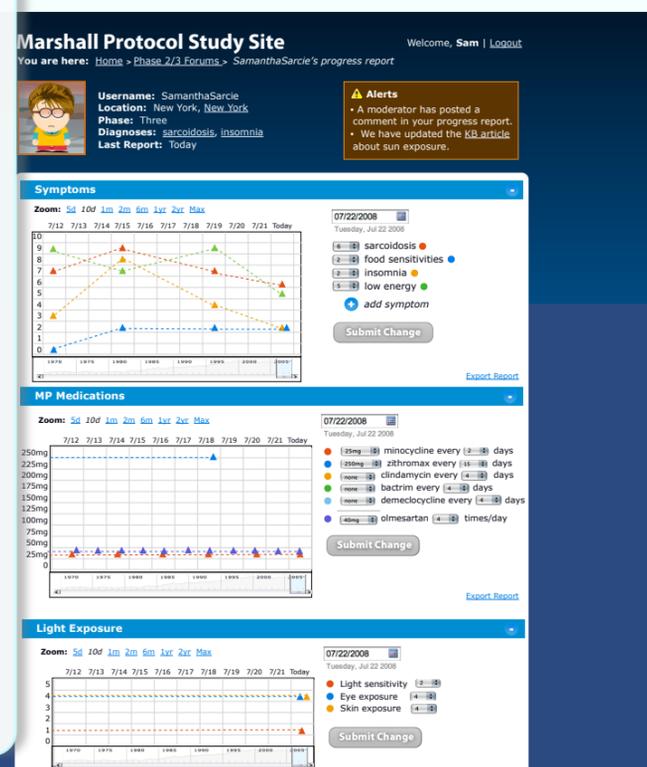


Marshall Protocol Study Site (in production)

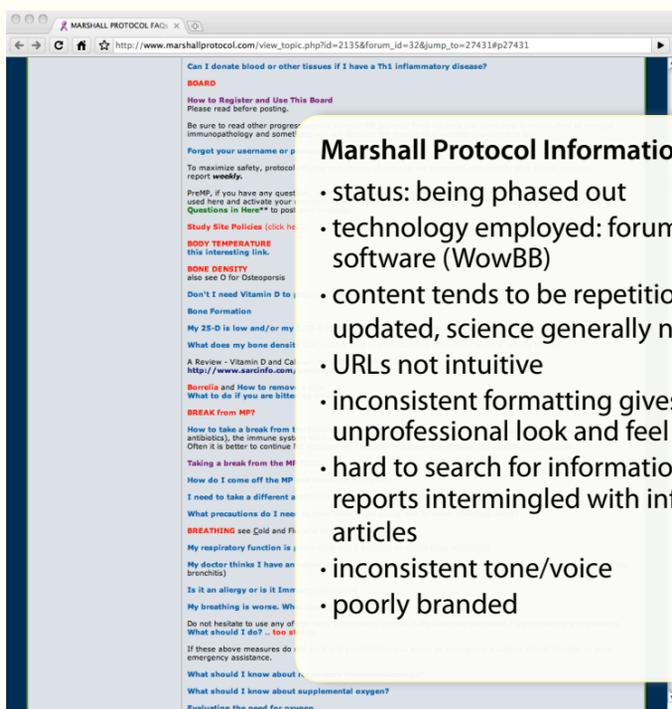
- status: in production since 2004
- technology employed: forum-based software (WowBB)
- search results indexed by date – not relevance
- URLs not intuitive
- data is unstructured and unsuitable for harvest/analysis
- poorly branded
- our experience: patients are willing to sacrifice some measure of privacy in exchange for support and help
- represents key obstacle

Marshall Protocol Study Site (in development)

- status: just beginning development
- last milestone completed: site dummy (right)
- technology employed: uncertain
- data will be well-structured and suitable for harvest/analysis
- one goal: export anonymized progress reports to relevant Knowledge Base article
- patients will be able to record, monitor, and analyze progress in an intuitive way (PatientsLikeMe model)
- physicians will be better equipped to monitor their patients
- key challenges: identifying suitable technologies; selecting user-friendly ontologies for diseases and medications; making the site highly usable for users who often suffer from cognitive dysfunction; and, finally, funding



Education



Marshall Protocol Informational Site

- status: being phased out
- technology employed: forum-based software (WowBB)
- content tends to be repetitious, not well-updated, science generally not well-cited
- URLs not intuitive
- inconsistent formatting gives posts an unprofessional look and feel
- hard to search for information: progress reports intermingled with informational articles
- inconsistent tone/voice
- poorly branded

Marshall Protocol Knowledge Base (MPKB)

- status: in production since 2009
- uses wiki software (DokuWiki)
- serves three key groups of stakeholders: physicians, patients, and researchers
- as of April 2010, 400 articles written, 27% of which are still being revised
- search results indexed by relevance (Yahoo! Search BOSS)
- 250+ terms automatically linked to relevant articles
- consistent look and feel
- articles are tagged
- ongoing goal: update content with recent studies which inform a metagenomic understanding of chronic disease

