Web 2.0 Offers New Opportunities for **Patient Care and Research**

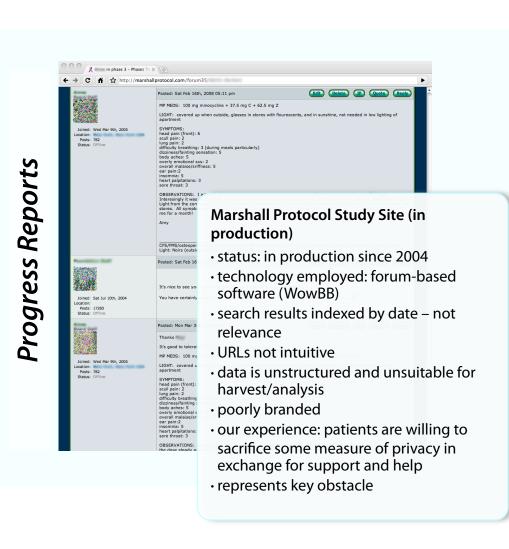
Paul Albert, Weill Cornell Medical College, New York, NY, U.S.A.

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



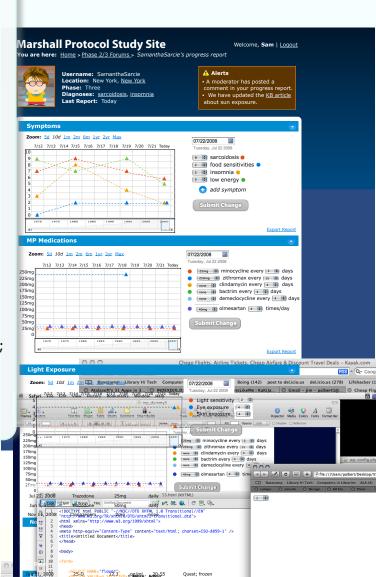
Autoimmunity Research Foundation A metagenomic understanding of chronic disease

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.



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

technology employed: forum-based

content tends to be repetitious, not well-

updated, science generally not well-cited

inconsistent formatting gives posts an

hard to search for information: progress

reports intermingled with informational

unprofessional look and feel

inconsistent tone/voice

poorly branded

status: being phased out

software (WowBB)

URLs not intuitive

articles

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How to take a break from t antibiotics), the immune syst Often it is better to continue Taking a break from the M do I come off the M I need to take a different

itions do I ne BREATHING see Cold and F

My respiratory fu

My doctor thinks I have an

Is it an allergy or is it Im

My breathing is worse. Wh

Do not hesitate to use any of What should I do? .. too st

If these above measures d

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

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s a place to get stions patients have about the II Protocol and the science which is it. Learn about:

all's theory of chr matory disease

duction to the MP – Length, Cost, In Interviews bility of the MP – Therapeutic pro hin D Metabolite Calculator

min D Metabolite Calculator tting Started – Checklist, Finding a sician, Working with a physician ing the MP – Light restriction?, Food & k, Immunopathology, @Phase One delines, Non-MP treatments Guidennes – wrnas
Phase Two/Three Notice for emergency

Autoimmunity Reviews rated "must read by prestigious literary awareness group "Faculty of 1000 Medicine"

Autoimmunity Research Foundation and the MPKB Project

immunity Research Foundation is a California-based 501©3 (tax deductible) non-profit formed to educate the public about t of, and study a treatment for, chronic inflammatory disease. The MPKB currently contains about 400 pages and draws from st possible evidence to support its mission. As of November 2009, about 70% of those articles are complete with the ider scheduled to be completed in the next year.

- e of Content (formerly on the home page) ct Status
- for using this resource bry and timeline of ARF

visions Recent changes Login

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