

The Patients Project



education

coaching

advocacy

patient education, coaching and resources



Patients gain stronger, more equal footing during their visits to their medical providers; this will result in better outcomes, fewer medical errors and healthier patients along with a reduction in the overall cost of our nation's healthcare. After our courses and seminars, we are available to work with patients or their caregivers in the role of **"health coaches" supporting them to navigate the healthcare system.** Or, if the situation requires it, we can refer the patient to an experienced patient advocate.

The Patients' Project is poised to become a leader in the groundswell grass roots movement to teach and coach those who have low health literacy, especially those who are from underserved communities, to become functionally health literate so they can make intelligent and informed decisions for their family and themselves. Through education, a mentorship approach and back-end coaching support, the goal of empowering patients to become confident, and active participants in their health and wellness care is attainable.

The Patients Project has unlimited outreach potential for educating patients using venues such as hospitals and clinics, doctors' offices, schools, support groups, community groups, and churches to disseminate information at small seminars. Our curricula will be available online in the future.

In 2001, it was estimated that low functional literacy resulted in an estimated \$32 to \$58 billion in additional health care costs.

Yes, it's pretty amazing.

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e.patients

In 2009, a group of patients were attending a medical conference on the latest research and treatments for neuroendocrine tumors (a rare cancer). Their conversation turned to how most had become e-patients through education and research and they were now empowered and educated partners in their own health care. Give someone who has a rare disease something to research and they become the ultimate hunter and gatherer. These patients, along with other pioneers, represent the newly emerging “e-patient movement.” They ask the right questions, find treatments and clinical trials, relate optimally to a team of physicians, are hospital savvy (patient’s eye view), are compliant with their medications, and can find support in a “wink”. As the conversation continued a patient asked “what if someone took the initiative to create a course to teach our acquired methodologies for navigating the healthcare community as well as our communication skills?”

Regardless of whether a patient is interested in wellness care for their family or has an immediate need for treatment,

they still need to know how to find resources, acquire, and then evaluate information. And so, *The Patients Project* had its heartbeat. Instructional courses would answer such critical questions as: how to find reliable information on the Internet, how to communicate with your providers, how to prepare for an office visit, organize and archive documents, how to read a prescription, and how to manage a medical crisis.

As the medical community continues to evolve, so will our methodologies for creating health literate and empowered patients—e-patients. This term, coined by the late Dr. Tom Ferguson, defines a new breed of informed health consumers who use the Internet to gather information about a medical condition of interest to them. Some of the effects of patients’ research online result in **better health information, better and more appropriate care, and different relationships with their physicians.** *Dr. Ferguson’s definition of e-patients are those who are equipped, enabled, empowered and engaged in their health care decisions.*

our mission



to educate and support the patient so that he becomes engaged in learning, confident and therefore empowered to advocate for himself by achieving a higher level of health care literacy including the skills to navigate the healthcare system

The Internet also provides the opportunity for what we call *virtual community outreach*. There are many, albeit virtual, professionally run support groups on the sociological, psychological and medical sides; and, they are not necessarily mutually exclusive. Through community-based outreach services, we will educate multitudes of patients through seminars, conferences and back-end support as “healthcare coaches” for under-served and special needs patients. If the patient can’t advocate for himself, and is finding it difficult to cope, The Patients Project will provide access to

professional patient navigators and advocates qualified to give beneficial support of all kinds. These advocates work with the families and medical providers of patients who are either too ill, too far away from their families, or their families don’t have the time to be effective. A patient advocate accompanies the patient on his journey through illness or injury and is an extra family member in times of crisis and can act and speak on the patient’s behalf. The Patients Project has partnerships with many sources of advocacy support and will recommend the appropriate resource for each patient.

patient centric^a_n_d simple language

Many companies that produce media and curricula to teach patients, do so for those in the business of healthcare— e.g., hospitals, care management groups, pharmaceuticals, and physicians. They produce videos about surgeries, chronic diseases, what to expect in the hospital and hospital safety programs. The purpose and goals of these types of media productions are: an increase in operational efficiency, enhancement of clinical outcomes, an increase in physician/patient communication, to help reduce malpractice lawsuits and increase physician loyalty through patient satisfaction. These programs are valuable and our unique, complementary patient-centric perspective takes communication to the next level.

Some of the goals of our programs are actually similar to those above, some aren't, but they are from the patient's perspective. Our bottom line goal is patient literacy and the know-how to navigate the system. This will reduce tragedies and accidents through misunderstandings and poor communication. Another goal for the patient is to lead a healthy life without the frustration and fear that ignorance can bring. We intend to produce our media and curricula to teach patients how to navigate their way through the health care system based on the acquired skills of an e-patient.



physician outreach

Our outreach efforts also include convincing medical professionals to take on the responsibility of encouraging their patients to become educated, especially those who have low health literacy. We encourage physicians to provide or recommend resources, including The Patients' Project so their patients can learn. This is crucial in today's technologically advanced medical world. Our goals include technological literacy for all—the "digital divide" still exists amongst the various socio-economic tiers of patients.

Board of Directors



If our mission is to educate, mentor and coach patients towards the goal of becoming their own advocates through healthcare literacy, we needed a strong founding Board of Directors who were educators, physician educators and those who believe fervently that this project will contribute to both the health of the nation and its healthcare system.

Carl Burak, MD, JD

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health literacy

is the ability to read, understand, and act on health information.

The **National Adult Literacy Survey** states that “as many as 44 million people (16 years and up) are functionally illiterate. An additional 53 million had only marginally better reading skills.” This translates into 50% of all adults may have problems understanding prescriptions, informed consents, insurance forms, even health education materials and doctors’ instructions. Two thirds of U.S. adults age 60 and over have inadequate or marginal literacy skills, and 81% of patients age 60 and older at a public hospital could not read or understand basic materials such as prescription labels.¹ In the low income population, about one-half of Medicare/Medicaid recipients read below the 5th grade level.



At risk populations include the underserved communities of the elderly, immigrants, minorities, low income populations, and those with chronic mental or physical health problems—mostly all populations with high illiteracy rates.

¹ Williams, MV. JAMA, December 6, 1995.



The Patients' Project

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**Members of NAHAC (National Association of
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