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Linking Connecticut Patients and Families to Reliable Health Information

In this issue: A visit to Colontown, cyber security, decision aids, and more!

Patient Advocacy Group, Colontown Gives Patients an Edge in Finding New Treatments

Colontown is a members-only Facebook page for colorectal cancer patients. Founder, Erika Hansen, a colon cancer survivor, is the Mayor of *Colontown*. Hansen started the site to help patients feel less isolated and to give them access to the most current information about clinical trials from other experienced members. The site is divided into 40 neighborhoods with names like Rectalburgh and Poop Shoot Group to help patients find others with similar diagnoses. On a section of the page called "The Clinic," members share personal anecdotes, report back from medical conferences, and learn about treatments under development from members who work in the drug industry. Members can also download a weekly spreadsheet of colorectal cancer trials culled from the *Clinicaltrials.gov* website. Read the article on Statnews.com to learn more.

Most People Know About Cyber Security Threats But Do Little to Protect Themselves Online

Despite a growing awareness of cyber crime, most consumers are complacent when it comes to protecting their personal information. According to a Norton survey of almost 21,000 consumers, most of us know it's risky to share passwords or to pay bills using the coffee shop's WI-FI, but we still do it. Even

cyber crime victims revert back to bad habits within a year of having their personal identity stolen. Surprisingly, Millennials are the most common victims of cyber crime. Intrigued? Click here to read more about the survey's findings and the simple steps you can take to protect yourself online.

New Decision Aids for Carpal Tunnel Syndrome, Uterine Fibroids, Parkinson's Disease and More

If you have been diagnosed with carpal tunnel syndrome you probably have lots of questions. What are my treatment options? Is surgery necessary? Can I wait and see? Decision aids are tools which lay out treatment or screening options in plain language for you and your physician to use in formulating your care plan. The decision aids offered by Dartmouth's Option Grid Collaborative are brief, one page tables or grids that summarize treatment or screening options based on latest available evidence. In addition to carpal tunnel syndrome, the Collaborative has also just rolled out grids for uterine fibroids, heavy menstrual bleeding, Parkinson's disease, depression, complex behavior problems in children, and lung cancer screening. Click here to learn more.

Childhood Hypertension Greatly Underdiagnosed

High blood pressure is one of the 10 most common chronic diseases in childhood, and places children at increased risk for heart disease as adults. Despite how common it is, it is widely underdiagnosed in the United States. Only 23 percent of children with elevated blood pressure readings in the hypertension ranges and about 10 percent of children with prehypertensive readings are actually diagnosed with high blood pressure. These findings are from a national study reviewing 15 years of health records for almost 400,000 thousand children published in the journal *Pediatrics*. According to one of the study's authors, pediatricians may dismiss a child's elevated blood pressure reading, saying it is due to being anxious or upset. Without a diagnosis, these children do not receive medication, and lifestyle changes to manage their condition. Recommendations for childhood blood pressure screening andtreatment of high blood pressure in children are available online.

Cellphones Pressed into the War on Zika

Did you know that the hum of mosquito wing beats is distinctive from one species to another? And, did you know that a simple flip phone can record mosquito wing beats accurately enough to distinguish between Culex mosquitoes, which spread West Nile virus, from Aedes mosquitoes, which spread Zika? Students at Stanford University's Bio-X institute are hoping cellphone user worldwide will record the sound of mosquitoes landing on them. The sound recordings could then be sorted by the embedded GPS and time coordinates to create a worldwide mosquito distribution map. Read more about "Shazam for Mosquitoes" in the *New York Times*.

Prescription to Learn (P2L)

Imagine a personalized health GPS which can cut through the information clutter on the internet and lead you to reliable sources which meet your specific needs. P2L is an interactive guide created by patients and caregivers to the best resources and solutions they have found for commonly-faced problems. Through P2L, patients and caregivers can personalize their search for information and support, find resources aligned with learning style preference, and view resource ratings from other patients, caregivers, and clinicians. Resources include websites, print materials, hotlines, online communities, mobile apps, podcasts, and videos. The site also offers apps to help patients stay organized and track their symptoms. P2L currently covers breast cancer, leukemia, and multiple myeloma. Resource guides to other conditions are under development.

Choosing the Right Medication

When it comes to choosing a medication, *Iodine* wants to help people find what works, faster. The company uses Google Consumer Surveys to collect data about what people actually experience when they take prescription drugs. Survey takers are asked: "Was taking the drug worth it over all? How well did it work for you? Is taking the drug a "hassle?" Interactive graphics distill and present the results from the surveys. *Iodine* presents data from published clinical research, physicians' reports to the FDA, and surveys of pharmacists. This data includes basic information on hundreds of drugs — their purpose, how they work, side effects and warnings, the upsides and downsides of taking a drug, prices, co-pays, and alternative drugs.

Cancer Clinical Trials don't Use Real-World Patients

Cancer drugs can be approved for use if clinical trials demonstrate an increase in patient survival or an improvement in the quality of life for cancer patients. Clinical trials are supposed to tell us how safe and effective a drug is for cancer patients in general, not just for those selected for the clinical trial. An article in the November 17 issue of *JAMA Oncology* reports that the benefit of most cancer drugs is marginal because the average patient in clinical trials is younger and healthier. The average patient is also better "plugged in to the healthcare system," better educated, wealthier, and has a better support system than the average cancer patient. All of these factors can support improved life expectancy. In short, clinical trials exaggerate the benefits real-world cancer patients will receive from new drugs.

New App Makes it Easy to Do Good When Shopping Online

"The greatest tool each one of us has to create change is the dollars we spend." This is the idea behind the free mobile app, and Chrome extension *DoneGood. DoneGood,* helps you find ethical and sustainable alternatives when you shop for anything online. Just type in the item you are looking for and *DoneGood* highlights socially responsible companies in your search results. *DoneGood's* creators, Cullen Schwarz and Scott Jacobsen have vetted hundreds of companies that do good (e.g. certified organic, fair-trade, certified B Corporations, and others) and offer unique, well-made products. You can download the *DoneGood* Chrome extension here, and the mobile app for iOS here. The company will release an app for Android devices soon.

Eating Gluten-Free

 If you have celiac disease, avoiding foods containing gluten is essential. You look for gluten-free labels as well as advisory notices warning of possible gluten contamination during food processing, transportation, and storage. Advisory statements are generally reliable, but they are not required under current food regulations. To eat confidently, celiac sufferers may consider subscribing to the food testing service, *Gluten Free Watchdog*. Founded by a registered dietitian, *Gluten Free Watchdog* tests foods labeled gluten-free as well as products that appear to be free of gluten-

containing ingredients but are not labeled gluten-free. Subscribers receive detailed reports of every new product tested and can search a database of over 425 products already tested. Consult the website for subscription rates and information about the diagnostic tests used.