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HEALTHNET NEWS

A newsletter for public librarians and others interested in consumer health information services

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NETNEWS

A GROWING HEALTH CARE PROBLEM..

Have you heard the medical term "C. Diff." more frequently recently?

A bacterial infection, Clostridium difficile, also known as C. difficile or C. diff, affects tens of thousands of people in the U.S. It has been occurring with increased frequency.

Its symptoms include watery diarrhea and abdominal pain, weight loss, and fever. In severe cases, it may cause colitis, inflammation of the colon.

Often contracted by people who have been hospitalized or have been taking antibiotics, recently C. difficile has also affected individuals who have not been hospitalized or taken antibiotics. Symptoms may appear weeks or even months after antibiotic use.

Some infected individuals never become ill but they can still transmit the infection to others.

It is more likely to affect adults over 65 and individuals who have had C. difficile previously.

C. Difficile was described as a "deadly diarrheal infection that poses a significant threat to U.S. health care patients," by Ileana Arias, principal deputy director at the U.S. Centers for Disease Control and Prevention, at a March 6, 2012 press conference - **http://www.cdc.gov/media/releases/2012/t0306_Preventing_DifficileInfections.html**

C. Difficile infections "increased several fold in the past decade and became more serious, but are nonetheless preventable."

This statement is a "key point" in a recent issue, focusing on C. difficile, of a U.S. Centers for Disease Control's Vital Signs publication. Vital Signs is a special CDC publication that highlights critical public health issues.

The Vital Signs consumer fact sheet about C. difficile appears online at **http://www.cdc.gov/vitalsigns/hai/**
A more detailed, technical version is available at **http://tinyurl.com/bmmv4yf**

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The federal Agency for Healthcare Research and Quality has published a Consumer Summary of research about "Treating and Preventing C-diff Infections" at **http://tinyurl.com/c46bfrv** Its consumer-friendly text is organized by topics such as "Is This Information Right for Me?" "Understanding Your Condition" and "Understanding Your Choices." It includes information about symptoms, causes, and treatment.

The Consumer Summary, written especially for patients, is based on a research report for physicians entitled *Effectiveness of Early Diagnosis, Prevention, and Treatment of* Clostridium difficile *Infection*, which was published in December 2011. The report describes C. difficile as a "growing health care problem,". The entire 263 page report is available online at **http://tinyurl.com/d5wvh8x** A much briefer Executive Summary is online at **http://tinyurl.com/d5u37oo**

The research report is one of a series in the Agency for Healthcare Research and Quality's Effective Healthcare Program. Many of the reports are based on systematic reviews of prior research studies.

This growing health problem offers another important reason for frequent hand washing and careful use of antibiotics.

IF YOU CAN'T AFFORD VACCINES FOR YOUR CHILD…

When your family pediatrician urges you to bring your child to the office for her vaccinations soon, it may be difficult to explain your reluctance to commit to an appointment.

Some parents are aware that their child needs to be immunized against whooping cough, meningitis, measles, polio, diphtheria, and tetanus, but do not have the financial resources to pay for these vaccines.

Financial assistance is available.

The Centers for Disease Control and Prevention, part of the U.S. Department of Health and Human Services, offers a Vaccines for Children (VFC) Program for financially eligible families. Free vaccines are available to children who meet certain criteria. Eligible children must be under nineteen years of age, Medicaid-eligible, uninsured, an American Indian or Alaskan Native, or underinsured. An underinsured child has health insurance, but the insurance does not cover vaccinations.

Under the Vaccines for Children (VFC) Program, vaccines are free but physicians may charge for administering the vaccine and for an office visit.

Details about the Vaccines for Children (VFC) Program, in English and Spanish, appear on the Centers for Disease Control and Prevention website at **http://www.cdc.gov/vaccines/programs/vfc/parents/flyer-vfc-parents.htm** Additional information for parents is online at **http://www.cdc.gov/vaccines/programs/vfc/parents/default.htm**

Certain physicians around the country are enrolled as VFC Program providers. If a child's doctor is not a VFC Program provider, public health clinics, Federally Qualified Health Centers (FQHC), and Rural Health Clinics (RHC) may provide this service.

Information about the Immunization Program of the Connecticut Department of Public Health is online at **http://www.ct.gov/dph/cwp/view.asp?a=3136&q=466892**

The Centers for Disease Control and Prevention publishes immunization schedules for children and adolescents at **http://www2a.cdc.gov/nip/kidstuff/newscheduler_le/**

The National Library of Medicine's Medlineplus website offers links to a variety of online resources about Childhood Immunization at **http://www.nlm.nih.gov/medlineplus/childhoodimmunization.html**

Additional health care assistance

Additional resources about financial help for health care are available within the "Navigating the Health Care System" Resource Guide on Healthnet's website at **http://library.uchc.edu/departm/hnet/**

Among the resources is "Programs that help People in Connecticut. Benefits Available/Who is Eligible/Where to Go," a joint publication of Northeast Utilities and the Connecticut Association for Human Services. It is available online in English and Spanish at **http://www.cahs.org/**.

Connecticut's Health Care Resource Guide appears on the Infoline 211 website at **http://www.211ct.org/referweb/landing.aspx** . It includes information about locating health care coverage when you are uninsured, finding assistance with prescription drug costs, and other health-related needs. **Infoline 211** is a free state-wide, 24/7 phone link to community agencies, services, and organizations. You may call **211** twenty-four hours a day, throughout the year, to speak with an Infoline information specialist about referrals to health and human services or for crisis assistance. This service is accessible to speakers of many languages and by people who use a TYY phone.

EXPLORING GENETIC TESTING

Will genetic testing help you to learn what medical conditions you may be destined to inherit?

Will testing teach you how to change your lifestyle to prevent diseases and medical conditions that your ancestors have passed on to you?

What information does genetic testing yield?

What exactly is a gene test?

Some authoritative websites explain the basics about genetic testing for health consumers.

Patient Page from JAMA/Journal of the American Medical Association

"Genetics: The Basics" is the topic of a one-page JAMA Patient Page at **http://jama.ama-assn.org/content/299/11/1388.full.pdf** . This brief overview of genetics is a good starting point for health consumers learning about genetics.

There is access to a collection of Patient Pages on a wide variety of health topics on the JAMA website at **http://jama.ama-assn.org/cgi/collection/patient_page?page=1**

National Human Genome Research Institute

According to a series of frequently asked questions (and answers "for patients and the public") about genetic testing, "Gene tests look for signs of a disease or disorder in DNA or RNA taken from a person's blood, other body fluids like saliva, or tissues."

This explanation is provided by the National Human Genome Research Institute, part of the National Institutes of Health, at **http://www.genome.gov/19516567**

The Institute's website describes the type of information genetic testing can provide. Genetic testing may offer a diagnosis for a patient with symptoms, determine if a person is a carrier for a disease, detect a genetic condition in an unborn child, screen newborns for "abnormal or missing proteins," reveal an inherited tendency for a disease, and discover which type of medicine is appropriate for a patient.

Information about specific genetic disorders, clinical research, and the importance of a family health history, written especially for patients, appears on the National Human Genome Research Institute website at **http://www.genome.gov/Patients/**

The Genetics and Genomics for Patients and the Public section of the Institute's website at **http://www.genome.gov/19016903** encourages individuals to gather a "Family Health Portrait," in order to help reveal patterns of diseases in parents and grandparents.

A Talking Glossary of Genetics Terms is available on the Institute's website at **http://www.genome.gov/Glossary/** The Glossary includes audio definitions, spoken by scientists from the Institute, as well as illustrations and 3D animations.

In the audio version, scientists from the National Human Genome Research Institute provide explanations of each of more than two hundred genetic terms in a consumer-friendly, low key style. Users of the Glossary may select English or Spanish explanations of the genetic terms. The definitions, and biographies of the scientists providing the explanations of terms, are also available in text form.

The Glossary is available as a free mobile phone app.

Users may employ an online form to suggest additional genetic terms for the Glossary.

There are multiple choice quizzes about genetics and genetic testing that yield scores (but not the correct answers) as well as an opportunity to print a certificate of completion that includes your score.

Labtests Online website

What about the pros and cons of undergoing genetic testing?

Labtests Online, a website published by the American Association for Clinical Chemistry, at **http://labtestsonline.org/** discusses the basics of genetic testing at **http://labtestsonline.org/understanding/features/genetics?start=9**.

The website warns of genetic testing's "benefits" and "limitations." It describes the testing as a "mixed blessing" since it does not provide a clear cut answer about a patient's chances of contracting a specific disease. Nor does it account for the effect of environment on one's chances of contracting a disease that may or may not develop.
Some diseases may be detected through genetic testing but do not have current methods of treatment.

Because of these cautions, the website urges those undergoing genetic testing to obtain genetic counseling to help in interpreting test results.

Kidshealth.org website

The Kidshealth.org website offers an overview of genetic testing and genetic counseling for parents at **http://kidshealth.org/parent/system/medical/genetic_counseling.html**

Genetics Home Reference website

The Genetics Home Reference website at **http://ghr.nlm.nih.gov/handbook/testing/directtoconsumer** urges health consumers to use caution in considering direct-to-consumer genetic testing that is marketed directly to patients. Physicians and genetic counselors provide an important perspective for patients that is lacking in direct-to-consumer genetic testing.

NEED INFORMATION ABOUT A GENETIC OR RARE DISEASE?

Genetic and Rare Diseases Information Center (GARD)

The *Genetic and Rare Diseases Information Center (GARD)*, at **http://rarediseases.info.nih.gov/GARD/AboutGARD.aspx** , a joint effort of the National Human Genome Research Institute and the National Institutes of Health's Office of Rare Diseases Research, provides information about diseases that affect fewer than 200,000 people in the United States. These details may include background information, ongoing research studies, and advocacy groups.

National Organization for Rare Disorders

The *National Organization for Rare Disorders* at **http://www.rarediseases.org/** is a federation of disease-focused organizations that advocates for patients with "orphan diseases" that affect fewer than 200,000 patients. These nearly 7,000 disorders involve more than 25 million patients and their families.

The organization's Rare Disease Database at **http://www.rarediseases.org/rare-disease-information/rare-diseases** describes more than 1,200 diseases. Disease summaries are brief and include a list of disease-related organizations and their web addresses. Access to full-text descriptions of diseases are free but require online registration. After registering, you may request a maximum of two full reports per day.

Health consumers may contact a NORD information specialist at **http://www.rarediseases.org/patients-and-families/patient-info** or by mail, fax, email, or phone to learn about clinical trials, resources and organizations. They may also ask questions of NORD's nurse or genetic counselor.

Genetics Home Reference website

The Genetics Home Reference website at **http://ghr.nlm.nih.gov/** "provides consumer-friendly information about the effects of genetic variations on human health." There is background information about more than 700 genetic disorders. This website is a service of the National Library of Medicine, part of the National Institutes of Health.

The website's online "Help Me Understand Genetics" Handbook includes a section on genetic testing that discusses costs, benefits, and risks of testing.

The website also contains an extensive glossary of medical and genetic terms.

FOR YOUR CONSIDERATION

The following titles are recommended to public libraries and other libraries providing consumer health information services. They are not part of the UCONN Health Center Library collection.

The Organ Donor Experience. Good Samaritans and the Meaning of Altruism.
Katrina A. Bramstedt and Rena Down. Rowman & Littlefield Publishers, Inc., 2011. 201 p. (ISBN 978-1-4422-1115-5 hardcover).

What motivates a person to undergo surgery and donate an organ to a person whom she does not know?

Author and medical ethicist Dr. Katrina A. Bramstedt has worked closely with medical centers evaluating potential living organ donors. She has been directly involved in the extensive medical and psychological testing that potential living organ donors undergo before hospitals determine if the donor is qualified to make this serious commitment.

Hospitals must determine that the living donor is making this offer without coercion and is donating the organ with no ulterior motive. Each Transplant Center must include an Independent Living Donor Advocate to counsel and evaluate the donor.

Despite the donor's generosity and sacrifice, organ recipients do not always survive or may have a limited length of survival. There are no guarantees of the donation's success.

This book explains the living donation process and its potential dangers. According to the United Network for Organ Sharing, the national nonprofit organization that coordinates transplants under contract with the federal government, "34 percent of living donors are not biologically related." These "Good Samaritan" organ donations comprise a minority of the more than 28,000 annual organ transplants in the United States.

The organ donors highlighted in this book are not necessarily individuals who have checked off the organ donor option when they renewed their driver's licenses. They are not people whose families donated their organs after their deaths. They are living individuals who have made an unusually generous, altruistic decision to donate an organ to a very sick patient in great need of a transplant.

What is unique about living organ donors…. about individuals who have decided to make this "extraordinary gift" to a stranger, a person who is neither a relative nor friend of theirs?

The book presents the stories of twenty-two donors, most of whom "expressed religious or spiritual values" as the source of their offer. In many cases, the donation was born of the donor's feeling of "abundance," her own good feelings of good fortune or thankfulness for recovery from personal suffering.

The book concludes with chapter footnotes, a bibliography, and web addresses for living donor organizations.

Information for potential donors and recipients is available on the website of the United Network for Organ Sharing at **http://www.transplantliving.org/** Additional information about becoming a living organ donor appears on the organization's website at **http://www.transplantliving.org/livingdonation/livingdonor/default.aspx**

Fragile Beginnings. Discoveries and Triumphs in the Newborn ICU. Adam Wolfberg. Harvard Health Publications Book. Beacon Press. 2012. 179 p. (ISBN 978-0-8070-1160-7 hardcover).

An obstetrician specializing in high risk pregnancies has a deep knowledge of the challenges that his patients, their families, and their newborns face. What if this background knowledge is enriched by real life experience?

While he was a resident in obstetrics and gynecology, Dr. Adam Wolfberg's wife gave birth to their third child prematurely, three months before the baby's due date, weighing under two pounds. The baby was born at Brigham and Women's Hospital, affiliated with Harvard Medical School.

After an uneventful pregnancy, this premature delivery was completely unexpected.

His baby suffered a unilateral grade 4 hemorrhage in her brain.

As a physician who specializes in obstetrics, Dr. Wolfberg could understand his wife's situation very clearly and could communicate on a very technical level with his colleagues caring for her, but he also experienced heightened fears about impending risks that his professional knowledge allowed him to understand very clearly. He "knew specifically what to worry about." (page 10) He was aware that infants who are born earlier than twenty-four weeks of pregnancy have a greater chance of succumbing than of living. Those who survive often suffer serious complications.

Dr. Wolfberg, parent and physician, offers a dramatic, informative retelling of his family's experience through his daughter's ninth year. As events unfold in his baby daughter's precarious birth, he intersperses medical information about premature births. He allows readers to understand the difficult challenges and emotions that he and his wife experience.

He describes his baby's care in the neonatal intensive care unit of the hospital. He explains in detail the serious potential complications premature newborns face, including lung disease, bleeding in the brain, and infections.

He explains that a child's outcome depends on the neuroplasticity of the baby's brain, the ability of brain tissue on one side to compensate for brain tissue on the injured side that had suffered a cerebral hemorrhage.

He recounts the history of medical care of premature infants and the history of medical, ethical, and legal decision-making that must be reached by doctors and parents and enforced by hospitals in cases of extreme prematurity when infants have little chance of survival.

A former journalist, Dr. Wolfberg frames his accounts of his family's experience and the history of premature newborn care so that the reader feels she is reading a novel, based on real life experience.

HEALTH FIRST! The Black Woman's Wellness Guide. Eleanor Hinton Hoytt and Hilary Beard. Smiley Books. 2012. 400 p. (ISBN 978-1-4019-3695-2 paperback).

Who are the usual caregivers within a family?

Women often fulfill the role of nurturer within their family and within their community.

But, when you are a mother, grandmother, or caregiver whom others depend on, it is difficult to provide needed "self-care" as well.

This book, especially for Black women from adolescence to mature adulthood, emphasizes that it is important that women consider their own needs as well.

Accustomed to caring for others, Black women, especially, need encouragement to make positive life choices to improve their own health.

Not only do they need to know the importance of eating nutritious food, maintaining a healthy weight, seeking medical care, and exercising, they must change prior patterns of putting themselves last when working toward good health. They need to reverse this traditional habit and put themselves and their own health needs first.

When Black women are healthy, they are able to provide better care for their family.

This realistic, contemporary book addresses the challenges of being "Black, female, and healthy" in American society in an honest, direct, informative style.

It includes specifics about the strains of family responsibility that often begin in adolescence, gaining independence in young adulthood, and facing health challenges in mature adulthood after of "lifetime of self-neglect."

The book incorporates discussions of "sexual and reproductive health, emotional health, tobacco and substance abuse," threats of violence in society, the influence of the role of Blacks in recent U.S. history, including the Civil Rights movement.

There are charts with diagrams and explanations of contraceptives, recommended health screenings and vaccinations for young, midlife, and mature women.

For each of the "ten top health risks for black women, " including diabetes, heart disease, obesity, stroke, kidney disease, and violence, the book provides suggested resources, including organizations and websites.

Each chapter begins with dramatic, true stories of Black women facing health challenges and crises.

Co-author Eleanor Hinton Hoytt is CEO of Black Women's Health Imperative at **http://www.blackwomenshealth.org/** a proactive health program established in 1981. Co-author Hilary Beard is an experienced health journalist.

The Autism Revolution. Whole-Body Strategies for making life all it can be. Martha Herbert with Karen Weintraub**.** Harvard Health Publications. Ballantine Books, 2012. 302 p. (ISBN 978-0-345-52721-9 hardcover).

Can a parent make changes in her child's life that will reduce symptoms of autism?

Can improvements in physical symptoms affect a child's autism symptoms?

This book offers some strategies and some guidelines for attempting changes.

Author Dr. Martha Herbert is an assistant professor of neurology at Harvard Medical School and a pediatric neurologist at Massachusetts General Hospital. She is director of the TRANSCEND Research Program at the hospital, a program that "explores possible abnormalities in the brains and bodies of children and adults with Autism Spectrum Disorders (ASD)."

However, according to Dr. Herbert, autism is a "complicated" condition, "so diverse that what works for one person won't work for another." She asserts that autism is not a "predetermined and fixed path. " She recommends a "whole body" approach. Despite the difficulty in improving autism symptoms, Dr. Herbert offers strategies because "small adjustments can sometimes trigger big changes."

She relates anonymous case histories of her own patients to illustrate her recommendations. Her narratives of children with autism and their families allow readers to hear the viewpoints of parents and children who experience autism.

Contrary to previous medical recommendations that informed parents that "autism is a genetic problem in their child's brain" and therefore has no chance of cure or improvement, Dr. Herbert asserts that there is no "autism" gene. "Autism involves the whole body."

Diet and other triggers may affect onset of autistic behavior. Genetic tendencies toward autism may be aggravated by stresses such as unhealthy food, toxins, infections, and life stressors.

In turn, alterations to diet and toxins may lead to positive responses. Changes in physical health may lead to unexpected improvements in autistic symptoms.

There are recommendations for further reading, both background books for parents, and "heftier," more technical readings. Chapter-by-chapter notes at the end of the book refer to medical research that reinforces her recommendations.

More information about autism spectrum disorders

Additional resources about autism spectrum disorders are available on the Healthnet website in the "Pervasive Developmental Disorders" section of the Mental Health Resources Subject Guide at **http://uchc.libguides.com/content.php?pid=78575**

"Why Are Autism Spectrum Disorders Increasing?" is the title of an article about a March 2012 report on the prevalence of autism in the U.S. by the Centers for Disease Control article at **http://www.cdc.gov/Features/AutismPrevalence/**

The website of a new Connecticut autism initiative, offered by the Department of Public Health at **http://www.ct.gov/dph/cwp/view.asp?a=3138&q=499610 ,** links to Connecticut and national resources for parents.

Written for parents, a review of autism spectrum disorder therapies, at **http://tinyurl.com/6stdydw ,** is part of the federal government's Effective Health Care Program, an ongoing research program that includes both technical and consumer health reports about the benefits and risks of different treatments for more than 30 health conditions. Reviews are written in Spanish and English.

Healthnet News is written by Alberta L. Richetelle and Judith Kronick.
If you have questions about anything in the newsletter or about Healthnet services for Connecticut public libraries, please call 860/679-4055; e-mail address: richetelle@nso.uchc.edu

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