



# Preventive Healthcare for Patients with Chronic Illness

Immune-mediated patients need regular “well” checkups, including up-to-date screenings and vaccinations, to ensure the whole person is treated.

By Ronale Tucker Rhodes, MS, and Kris McFalls

Individuals with an immune-mediated disease often are so focused on tending to their chronic illness-related health needs that they neglect to practice preventive healthcare. In fact, not remembering to regularly see their primary care physician is the norm simply because there are so many other frequent visits to their various “ologists.” But, having a chronic illness can put patients at a higher risk for other diseases, making it even more important to be proactive about their overall health. This includes having regularly scheduled visits with a primary care physician (PCP), getting regular screenings and keeping up to date on vaccinations.

## The Specialist-PCP Connection

Regular checkups with a PCP are often referred to as “well visits,” whereas visits to a specialist typically are

“chronic care visits.” What’s the difference and why is it important? First, well visits are generally more comprehensive and involve planning and education on the part of the patient and the physician. For instance, at the basic health level, most individuals are unaware of what screenings or vaccinations are needed and when, and they don’t know that they should ask their doctors what is recommended. On the other hand, many PCPs may not be as well-versed about the patient’s chronic condition as they could be, so communication between the PCP and the patient is especially necessary.

When it comes to chronic care, specialists and PCPs have very different roles and, often, there is a lack of communication between the two. Dr. Marc Reidl, MD, MS, assistant professor of medicine, clinical immunology and allergy at the University of California, Los Angeles,

explains that chronically ill patients often have multiple, complex medical conditions, and it is the specialist's role to provide detailed recommendations and advanced management of a specific condition. Ideally, this will optimize the patient's health with regard to that specific issue. In addition, as medical diagnosis and treatment become increasingly complex, specialization is necessary to keep up with the vast amount of information in any specific area. "This focus allows a specialist to develop expertise through education and experience that the PCP may not possess," says Reidl. "However, the specialist care is no substitute for the overall comprehensive care provided by the PCP, and sometimes, specialists can miss 'the big picture,' because they are so focused in one area."

According to Annette Zampelli, MSN, CNRP, medical science liaison at CSL Behring Biotherapies for Life, the PCP is viewed as the "gatekeeper" of the patient's health information, including making sure that redundancy is not occurring regarding labs, tests, etc. And while, ultimately, this should be the PCP's responsibility, often it is the patient who communicates the information that avoids duplication. Ideally, says Reidl, there is regular communication between the specialist(s) and the PCP, and it is often the practice of specialists to report their findings and/or recommendations to the PCP. However, he adds, "there is no formal protocol for this interaction. My general advice to patients is to be their own advocate [and] make efforts to get all their clinic records and reports to ensure [their] PCP has information from all involved specialists."

### **Screenings Are Twice as Important**

Chronic illness predisposes patients to certain other diseases, including cancer. A recent survey conducted as part of the Gallup Healthways Well-Being Index, and based on telephone interviews with more than 350,000 adults in the U.S., found that individuals who have had a heart attack or chronic illness may raise the risk of being diagnosed with cancer. Those with high blood pressure, high cholesterol or diabetes were about twice as likely to have cancer as healthy people without these chronic illnesses.<sup>1</sup>

Cancer screenings of particular importance to immune-mediated disease patients include the prostate-specific antigen test to screen for prostate cancer in men, which should be conducted annually in high-risk patients beginning at age 40 to 45; annual mammograms and Pap smears to test for breast, pelvic and cervical cancer in women beginning at age 40; and colonoscopies and fecal occult blood screenings to test for colon cancer in both

men and women, with the first normally recommended at age 50 and then every 10 years, depending upon personal medical and family histories.

Other annual screenings also are of importance. Vision should be regularly checked (especially for those with autoimmune disease), as should hearing (particularly for those with chronic ear infections). Because obesity and being overweight are major risk factors for chronic disease in the general population, patients with immune diseases who are already at higher risk for chronic diseases especially need to maintain a healthy weight. Studies show that extra fat is a reservoir for toxic chemicals that can have an adverse effect on many cell types and, thus, is a cancer promoter. Therefore, body mass index should be regularly measured.

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Individuals with immune-mediated diseases also are more prone to cancers such as lymphoma and skin cancer. Those with either a primary immune disease or an autoimmune disease who are on immune-suppressing therapy have an impaired ability to control or kill infectious agents and environmental toxins, putting them at higher risk for lymphoma. As a precaution, the lymph nodes should be regularly checked. And, patients on immune-modulating medications and frequent antibiotics have a higher risk of sun-related skin damage from UV radiation exposure. So, it becomes even more important to annually scan for and document any changes in skin pigmentation and growths.

Blood work is often part of both the specialty visit and the PCP visit. Patients on immune-modulating medications usually will have a complete blood count (CBC) test and a chemistry panel every three to six months depending on their medication. Blood tests performed at the yearly

screening that are not normally included in the specialist screening should include a CBC with differential and platelet count, a uric acid test, erythrocyte sedimentation rate test, C-reactive protein test and a lipid panel that tests for cholesterol levels.

### **Which Vaccinations, Why and When?**

All individuals require some vaccinations at intervals throughout their lives, regardless of their health status. Vaccines can be grouped into four major categories: live, attenuated; dead, inactivated; component or conjugate; and toxoid. PCPs may avoid giving immunocompromised individuals live viral vaccines, such as measles-mumps-rubella (MMR) or chickenpox (varicella) vaccines, because a compromised immune system can't recognize and fight off bacteria, viruses or other germs the way a healthy immune system can. However, which vaccines are recommended for those with a weakened immune system depends on their particular condition.<sup>2</sup>

Live, attenuated vaccines usually are created from the naturally occurring germ itself. The germs used in these vaccines still can infect people, but they rarely cause serious disease. These vaccines include:

*Chickenpox.* Also known as varicella, chickenpox is extremely contagious, spread through the air when people sneeze or cough, or through an infected person's chickenpox sores. Most children are vaccinated against chickenpox at 15 months old. People ages 13 years and older who were not vaccinated as children need two doses of the chickenpox vaccine. Once chickenpox is contracted, it is very rare but possible to get it again. It's more common for people who have had it to develop shingles, caused by a reactivation of the same virus, later in life.

*Measles, mumps and rubella.* Most adults today are immune to measles, mumps and rubella either because they have had the diseases as children or they have been vaccinated against them. People born in or after 1957 have likely received at least one dose of the measles-mumps-rubella (MMR) vaccine. However, those born before 1957 who don't think they've been vaccinated should be, and healthcare workers and individuals who travel outside of the U.S. are advised to get a second dose.

*Shingles.* Although shingles, caused by a reactivation of the chickenpox virus, typically occurs in adults later in life, adults of all ages have been known to get this disease. One dose of the shingles vaccine is recommended only for adults age 60 and over.

*Rotavirus.* Rotavirus is the most common cause of severe

diarrhea among children, and approximately 55,000 children in the United States are hospitalized each year, while more than 600,000 children die from it annually worldwide. The disease is characterized by vomiting and watery diarrhea for three to eight days, and fever and abdominal pain frequently occur. Repeat infections can occur, but they tend to be less severe than the original infection. A series of three doses of the rotavirus vaccine is recom-

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mended in children at ages 2, 4 and 6 months. Infants diagnosed with severe combined immunodeficiency syndrome (SCID) should not receive rotavirus vaccine.

*Influenza (nasal spray).* The nasal spray flu vaccine (sometimes called LAIV for live attenuated influenza vaccine) is a vaccine made with live, weakened viruses that cannot grow at normal body temperature. Given via a nasal sprayer, this vaccine was approved for seasonal influenza viruses in 2003 and tens of millions of doses of the vaccine have been given in the United States. LAIV is approved for use in healthy people 2 to 49 years of age who are not pregnant. People with illnesses that weaken the immune system, or who take medications that can weaken the immune system, should not be vaccinated with LAIV.

Inactivated (killed) vaccines cannot cause an infection, but they still can stimulate a protective immune response. Viruses are inactivated with chemicals such as formaldehyde. Inactivated vaccines include:

*Influenza.* Because flu viruses change all the time, flu vaccine is reformulated every year to provide protection against the three most prevalent virus strains in circulation. Flu shots are needed between September and mid-November each year to give an individual's body time to build the proper defense. The flu shot both prevents and controls the flu.

*Polio.* While polio has been eliminated from the Western Hemisphere, it has not been eradicated in the rest of the world. Most children are vaccinated against polio in four different doses, the first three before 18 months of age, and the last before 6 years old. Teens who have not completed their series of polio vaccines and are not yet 18 years old are advised to complete them.

Conjugate vaccines are made by using only parts of the



viruses or bacteria. These vaccines cannot cause disease, but they can stimulate the body to produce an immune response that protects against infection with the whole germ. Five of the newest vaccines are made this way:

*Pneumococcal disease.* Pneumonia is a serious disease affecting the lungs, and the bacteria that form from this disease can attack other parts of the body, including the brain, which can cause meningitis. The Centers for Disease Control and Prevention (CDC) recommends that people over the age of 65 get the pneumococcal vaccine one time. If an individual has received this vaccine before age 65, and it has been longer than five years, the CDC recommends a second shot. Individuals ages 2 through 64 who have diabetes or chronic heart, lung, liver or kidney disorders should also get a pneumococcal vaccine.

*Haemophilus influenzae type b.* Hib disease, caused by a type of bacteria, usually strikes children under 5 years old. A child can contract Hib disease by being around other infected children or adults, as the germs spread from person to person. If the germs stay in a child's nose and throat, the child probably will not get sick. But if the germs spread into the lungs or the bloodstream, they can cause serious problems. Before the vaccine, Hib disease was the leading cause of bacterial meningitis among children under 5 years old in the United States. All children should be immunized with the Hib vaccine. And while children over 5 years old usually do not need Hib vaccine, some older children or adults with special health conditions should get it.

*Meningococcal disease.* Meningitis has seen a resurgence in the U.S. Approximately 2,600 people in the U.S. are diagnosed with meningitis, and about 10 percent to 15 percent of those people die. Meningitis is a viral or bacterial infection of the fluid of a person's spinal cord and the fluid that surrounds the brain. It is spread through the exchange of respiratory and throat secretions (i.e., coughing, kissing). Symptoms include high fever, headache and stiff neck, which can develop over several hours, or they may take one to two days to appear. Other symptoms may include nausea, vomiting, discomfort looking into bright lights, confusion and sleepiness. All young people ages 11 through 18, as well as college freshmen living in dormitories and individuals with special medical conditions, should be vaccinated against this disease.

*Hepatitis A and B.* Approximately 12.5 million Americans have been infected with hepatitis B virus at some point in their lifetime, and about 5,000 people die each year from hepatitis B-related liver disease. The number of new infections per year is declining due to routine hepatitis B vaccination in children and adolescents. But, even if vaccinated as a child, vaccines to protect against hepatitis A and B are recommended for individuals in high-risk groups, such as healthcare workers, those who live in households and/or have sex with people with chronic hepatitis B, those with multiple sex partners, people with a recently acquired sexually transmitted disease, men who have sex with men, and injecting drug users.

*Human papillomavirus.* HPV, known to cause cervical cancer, is now believed to cause other women's cancers like vulvar and vaginal. The three-dose HPV vaccine is recommended for all females ages 11 to 26, and could be given to females as young as 9 years old.

Toxoid vaccines are made by treating toxins (or poisons) produced by germs with heat or chemicals, such as formalin, to destroy their ability to cause illness. Even though toxoids do not cause disease, they stimulate the body to produce protective immunity just like the germs' natural toxins. These include:

*Diphtheria, tetanus and pertussis.* While tetanus is not spread from person to person, it is caused by a toxin that enters through the skin. Common signs include headache and muscle stiffness in the jaw initially, and then stiffness in the neck, difficulty swallowing, muscle spasms, sweating and fever. Diphtheria, on the other hand, is also caused by a toxin, but it can also spread from an infected person to the nose or throat of others. In some instances, it can lead to breathing problems, heart failure, paralysis and some-

times death; in others, it can cause sores on the skin that are painful, red and swollen. Pertussis (whooping cough) has recently been on the rise, and is easily spread and most dangerous in babies younger than 1 year old. In 2008, 19,000 whooping cough cases in adolescents and adults were reported to the CDC. Most children receive a combined diphtheria-tetanus-pertussis (DTP) vaccine, and adolescents and adults need a Tdap vaccine followed by a Td booster every 10 years.

Many organizations, including the CDC, Immunization Action Coalition, American Academy of Pediatrics and most state health departments, publish immunization schedules. While some are more in-depth than others and list medical conditions as factors, all follow the same general guidelines.

### Keeping Up-to-Date Records

No central repository of records exists, so to keep current on screenings and vaccinations, patients need to keep up-to-date records. Some PCPs encourage patients to keep records by providing vaccination record cards for patients to track immunizations and the dates they were received. This card should be kept in a safe place, while a copy of the card should be kept handy in a purse or wallet.

*When the lab tech is drawing blood, patients should request that their PCP be sent copies of all lab results.*

If individuals can't locate a record of whether they've been immunized for a particular disease, "there is a blood test called the antibody titer that can detect the presence of antibodies against the disease in question. If the level of these antibodies is high enough, it is a good indication that they have immunity to the disease and do not need another vaccination."<sup>3</sup>

Blood work also should be logged. When the lab tech is drawing blood, patients should request that their PCP be sent copies of all lab results. By writing both the PCP's and specialist's fax numbers on the lab sheet, patients can help to ensure the lab sends the results to both physicians. This

will also help to decrease the risk of unnecessary duplicate testing at the well visit.

A free service from Google — Google Health — may offer an easy solution to maintaining immunization records, as well as a complete repository for all kinds of personal health information. At [www.google.com/health](http://www.google.com/health), it's possible to create online personal health profiles, including health conditions, medications, allergies and lab results by importing medical records from hospitals and pharmacies. Sharing health records within an approved care network is another feature, as well as browsing an online health services directory to find services that are integrated with Google Health. Competitor offerings include Microsoft's HealthVault and the Indivo project (an open-source project managed by the Children's Hospital Informatics Program).

### The Patient as Advocate

The need for regular well visits, in addition to specialist visits, to ensure overall good health cannot be overemphasized for patients with immune-mediated diseases. This dual supervision makes certain that the whole person is treated, rather than just the chronic illness. Routine screenings and immunizations at well visits help keep routine, simple problems from being overlooked. They also can help to prevent serious infections in chronically ill patients.

Maintaining good communication between the patient's PCP and "ologists" is essential to keeping the PCP current with the patient's chronic illness, plus helps to eliminate duplicate testing and, even, medication errors. But, patients need to take responsibility, too. They must act as their own advocate, making regular appointments, encouraging communication between physicians, asking questions and maintaining up-to-date and accurate healthcare records. ■

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### References

1. Warner, J. Cancer Linked to Other Chronic Illnesses. WebMd, Apr. 2, 2010. Accessed at [www.webmd.com/cancer/news/20100402/cancer-linked-other-chronic-illnesses](http://www.webmd.com/cancer/news/20100402/cancer-linked-other-chronic-illnesses).
2. Vaccines when your immune system is compromised. MayoClinic.com Health Library. Accessed at [www.riversideonline.com/health\\_reference/Infectious-Disease/AR00016.cfm](http://www.riversideonline.com/health_reference/Infectious-Disease/AR00016.cfm).
3. Healia Health Guides. How Do I Know if I Have Been Properly Vaccinated? Accessed at <http://www.healia.com/healthguide/guides/vaccines/how-do-i-know-if-i-have-been-properly-vaccinated>.