

## Concerns about Antibiotics, Vaccines, and Medical Tests

### Do I need to take an antibiotic?

Yes, all patients on CYC need to take an antibiotic to protect against a common form of pneumonia (*Pneumocystis carinii* pneumonia). We recommend Bactrim, one single-strength tablet a day. If you are allergic to sulfa medications, you cannot take Bactrim. In that case, we recommend Dapsone 100 mg or Atovaquone 1500 mg twice a day. You will need to take an antibiotic the entire time you are taking CYC and perhaps for several weeks longer.

### Should I get the flu vaccine?

The flu (influenza) vaccine is recommended every year. Patients with potentially suppressed immune systems should be especially careful to get annual flu shots.

### Should I get the pneumococcal vaccine?

Pneumococcal (pneumovax) vaccine is recommended for patients with long-term illnesses or elderly patients. This vaccine will provide protection against pneumonia for 5-10 years.

### Does my white blood cell (WBC) count affect my treatment?

Causing a low WBC count is not a goal of treatment with CYC. If the WBC count is  $3,500/\text{mm}^3$  or less, CYC is stopped for 10 days. Once the WBC count is greater than  $3,500/\text{mm}^3$ , CYC is restarted at a lower dose. A WBC count below  $3,500/\text{mm}^3$  can be dangerous.

### What can I do to make sure that my WBC count isn't too low?

Get blood tests as ordered — every 2 weeks. Remember: the goal is to keep your WBC count above  $3,500/\text{mm}^3$ .

### Once I am off CYC, will I still need blood and urine tests?

After CYC, many patients switch to another medication (e.g., methotrexate, azathioprine, or mycophenolate mofetil). This new medication assumes the job of controlling the vasculitis. When taking the new medication, you will also need to continue getting regular blood and urine tests.

CYC can cause bladder cancer many years *after* patients stop CYC. For this reason, you will need to get a urine test (i.e., an urinalysis for “dipstick and microscopy”) every year after stopping CYC. Urine tests are designed to detect blood in your urine, which may be an early sign of bladder cancer.

### Is there anything that my doctor at home needs to check on?

Your primary care physician or rheumatologist at home should arrange for the tests and check your blood and urine results. Between visits to the Vasculitis Center, it is crucial to have follow-up by physicians close to home.

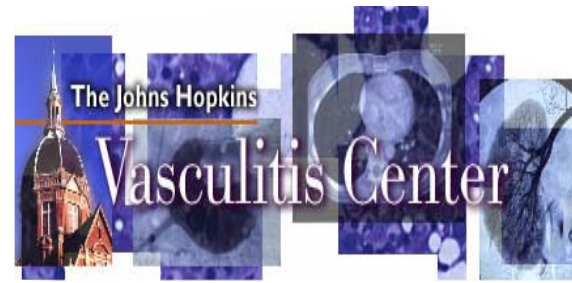
### Can I have children when on CYC?

There may be harmful effects on the baby if you conceive a child while on CYC. Both men and woman should use an effective form of birth control while taking CYC. Attempts to conceive should not occur until at least 3 months after stopping CYC.

### Will I be able to have children after taking CYC?

CYC causes infertility in some (but not all) patients. The risk of infertility increases the longer you take the drug. Patients over the age of 30 are more likely to become infertile.

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<http://vasculitis.med.jhu.edu>



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If you are interested in knowing more about how you can support the missions of The Johns Hopkins Vasculitis Center in discovery, teaching, and patient care, please contact:

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## Cyclophosphamide



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## CYCLOPHOSPHAMIDE

Cyclophosphamide (CYC) is used to treat serious forms of **vasculitis**. Variants of this disease treated with CYC include Wegener's granulomatosis, microscopic polyangiitis, Churg-Strauss syndrome, polyarteritis nodosa, Takayasu's arteritis, Cogan's syndrome, Behcet's disease, central nervous system vasculitis, and others.

The decision to recommend CYC is an important one. At the Vasculitis Center, we prescribe CYC when a patient's disease threatens the ability of an organ to function or poses a threat to the patient's life.

We have designed this pamphlet to inform you about the potential side-effects of CYC. You need to be aware of these potential side-effects. You also need to understand what you and your doctors should do in order to monitor your condition while you are on CYC. We present our approach to the use of CYC in a format that incorporates the most frequently asked questions of Vasculitis Center patients.

We ask that you read this information carefully and share it with your other doctors. Please feel free to ask any further questions you may have after reading this pamphlet.



## Potential Side Effects and Preventive Measures

### What are the possible side-effects of CYC?

CYC is the most powerful medicine we use to treat vasculitis. Without it, many forms of vasculitis would be fatal. But the effectiveness of CYC has certain trade-offs, and these are its potential Side-effects.

The main side-effects of CYC include:

- Serious bladder inflammation and bleeding from the bladder wall
- Anemia (low red blood cell count), which causes fatigue
- Low platelets, which leads to a risk of bleeding
- Risk of infection that increases if the WBC count becomes low
- Infertility (in women and men)
- Premature menopause in women
- A higher than normal risk of developing certain kinds of cancers (e.g., leukemia, lymphoma, myelodysplastic anemia, skin cancer, and bladder cancer).

Because of these potential side-effects, we only use CYC for cases of severe vasculitis. We employ this treatment for as short a time as possible.

### What can I do to help prevent the potential side-effects from CYC?

The following steps are essential:

- Get blood & urine tests every 2 weeks
- Drink at least 8 eight-ounce glasses of water a day
- Take the antibiotic (Bactrim, Dapsone, or Atovaquone) prescribed along with CYC every day
- Follow up at the Vasculitis Center as instructed
- Keep in close touch with your primary care physician

## Frequently Asked Questions

### How does CYC work?

CYC works by suppressing the immune system. By doing this, it progressively dampens the inflammatory process associated with active vasculitis. The aim of using CYC is to push the disease into remission (inactivity) as soon as possible, before the inflammation causes permanent organ damage.

### Is it better to take CYC in small doses every day, or in large doses every month?

CYC can be taken in tablet form (once daily), or as an intravenous injection (usually once a month). Studies have suggested that daily oral CYC (i.e., tablets every day) leads to longer remissions. We also believe that the medicine and its side-effects can be controlled more safely if used in small daily doses rather than in large monthly doses. Thus, at the Vasculitis Center, we usually use the daily oral form.

### Is CYC "chemotherapy"?

Not in the sense that cancer drugs are chemotherapy. CYC was developed initially to treat cancer. However, the doses of this medication used in the treatment of vasculitis are far lower than those used to treat cancer.

### Will I be very sick like patients who are on "chemo" for cancer treatment?

In cancer patients, CYC is used in extremely high doses and is administered intravenously. True chemotherapy is often associated with nausea and vomiting in the days after it is given. However, in the

doses of CYC that we use to treat vasculitis, the medication does not cause the side-effects of severe nausea and vomiting that patients on cancer chemotherapy often get. Some patients experience mild stomach upset, but severe nausea is very unusual.

### What are the strengths of CYC tablets?

CYC comes in 25mg and 50mg tablets.



### When should I take CYC?

First thing in the morning, all tablets together. This gives you all day to wash the drug through your system by drinking ample quantities of fluid: the eight 8-oz. glasses referred to earlier.

### Will I lose my hair?

Patients usually don't lose all of their hair, but many notice significant thinning. Once CYC is stopped, the hair usually grows back gradually.

### How long will I be on CYC?

Many patients need treatment for 6-12 months. If possible, we try to decrease the treatment length to 3 to 6 months. The decision to discontinue CYC and switch to another drug depends on how the patient responds to the treatment. We aim to minimize the length of time our patients are on CYC, because of the drug's many potential side-effects.