

# Lymphoma Survival

## June 2011 Newsletter

*Strive>>Survive>>Thrive*



Photo by Svet: "Springtime Inspiration"

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*June, beautiful June!*

*For me, June eclipses birthdays, Christmas and yet another New Year's Eve.  
June is the month of renewal, of rebirth, the anniversary of life itself.*

*The energy source of all living things reaches its zenith, and the eagles soar to  
celebrate the event. The ocean calls instinctually to a mysterious, earlier time.  
Outdoor opportunities engage the inner will-to-live. Active days yield easily to  
gentle, long, warm evenings with time to reflect and give thanks.*

*The autumn years can wait. For now, the measure of my life will forever be tallied by the number of Junes remaining.*

Robert G. Miller

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## **Introduction**

*Indeed, our opening comment for June is timeless. With follicular lymphoma, life takes on a new perspective. Issues become relative. We reflect on what's important, thinking as much about quality as quantity for the remainder of the journey.*

*Here, along the trail, a fresh breeze off the ocean mingles with the delicate fragrance from eager little wild flowers amidst the scent from the evergreens. The creek gurgles with the pristine essence of life. Eagles play with each other.*

*The spirit tree with ageless wisdom states in silence: “Fill your lungs” boy...this is the “thrive zone” ...at least for now...and you’re damn lucky to be here for another June!*



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*Our membership renewal process takes place each month. Every so often I like to welcome back our renewing members for another year.*

*The original group was entered into the current database over seven years ago with some of those being here long before that. It’s truly gratifying to hear from many who are doing well, helped in some measure, from their own words, by the information offered here.*

*Special thanks go to many for their generosity and kind words of support. As noted, your support makes it all come together month after month, with “heart and soul”, dedicated to the cause, knowing it’s making a difference. As a result of this support we are pleased to freely offer our full services to everyone.*

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*While on the subject of what makes it all tick, special thanks goes to Jill and Sue, our discussion board moderators. This forum, now in operation for over three years, has grown in popularity. It has taken on a stature of quality with a depth of reliable research, guidance and personal support not seen elsewhere. (Heck, my absence just makes it run all the better!)*

*Thanks also to Sands, our original moderator...such a stalwart gal in the Nevada high desert country...still without treatment for about a decade, glass of “red” in hand, still with her chlorambucil pills in the fridge it would seem.*

*And thanks to Svet who provides our beautiful monthly photos, and to Judith, our administrative manager, for her vital work every day in keeping the records straight.*

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*For the last few months, the new science of epigenetics has been emphasized in controlling fNHL for long-term success. The May 2011 newsletter was devoted entirely to that topic, this being seen as a top priority for all those who have achieved clinical remission.*

*Our emphasis this month switches back to treatment related issues, notably increasing controversy in connection with rituximab from the experts, and the ever present controversy associated with scans. Members seeking credible medically supported treatment options “outside the box” should find item #2 of interest. Item #3 is somewhat of a departure, but a topic that members should find informative, relevant and significant. And finally there are a few nuggets to spice the whole thing up.*

### **1. (Maintenance) Rituximab...Latest Expert Opinions...a Must Read**

Termed by some as a “miracle”, affectionately by others as “vitamin R”, with time we are now seeing some concerns with rituximab being raised by the experts.

*I had rituximab myself for the first time in year 20 in combination with the GDP (gemcitabine, dexamethasone, cisplatin) protocol (see Article #6, “Treatment Options” and past newsletters from 2008/09).*

Without doubt, over the past 10 years, the monoclonal antibody, rituximab (Rituxin, Mabthera) has generated more attention, publicity (and money) in the follicular lymphoma community than any other drug or item of research. In 2010 alone revenues from the sale of rituximab exceeded \$5 billion, most of which was from treating lymphomas.

It is not our role here to play either advocate or naysayer, but rather to bring the latest information from the most credible experts to the attention

of our members; personal viewpoints being expressed with balanced objectivity.

## **Background Facts**

First, some background, much of which has been lost over the last 10 years as rituximab has taken on a different role than what was first envisioned for the drug.

In the late 1990's shortly after approval following clinical trials, rituximab was anticipated to be a stand-alone follow up drug to standard chemo regimens with the goal of extending overall fNHL survival with minimal toxicity, since it had been well established over many years that chemo drugs, even the more toxic combinations, were incapable of doing so.

Interestingly, the dosage of rituximab used in the initial research and in subsequent trials was never tested to determine its effectiveness at various levels. The current standard dose was seen to work and so with the patent time clock now running, rituximab was expedited into the marketplace. As an aside, it would be interesting to know if lower doses would be effective, as some have speculated, but that isn't likely to be tested since the patent apparently expires in 2015, less than four years away, at which point numerous so-called "bio-similars" are waiting in the wings.

Although foreseen as follow up therapy to chemo as mentioned above, patients and doctors alike were attracted to rituximab's apparent low toxicity and so, primarily in the USA, although unapproved in the application, some doctors administered rituximab as front-line therapy to their fNHL patients in what is termed an "off-label" application. In this setting, it was found that rituximab provided a median time to relapse of about 12 months, but only about 70% of the patients developed a response. This latter point is important to remember, since it would seem from this experience that upwards of a third of patients, despite having the CD20 "docking point" for rituximab (as noted on the pathology report), have little or no clinical response to the drug.

## **Rituximab with Chemotherapy**

During the early years when rituximab was being used in the approved application on its own following standard chemo treatment it was observed that patients seemed to be relapsing at a slower rate than on chemo alone and so trials were done with rituximab combined with chemo. In virtually every case, R-Chemo yielded a longer median time to relapse than chemo alone.

Thus, the use of rituximab quickly gained almost universal application for the thousands of patients who would require treatment at some point in their journey.

Rituximab also resulted in a significant breakthrough for those planning an autologous stem cell transplant by “mopping up” (most) remaining lymphoma cells prior to the harvesting procedure.

### **Maintenance Rituximab**

With all this success, apparently on every front, it was inevitable that rituximab would be considered for use in an ongoing fashion similar to what was originally envisioned. The idea would be to treat fNHL patients with the drug at various time periods with the goal of holding the lymphoma in check (at least for awhile). Trials were run, and indeed it was shown that “progression-free survival” (definition below) was extended for those receiving regular infusions of the drug. The practice has become well known as “maintenance rituximab” (MR).

That brings us to the present time for which enthusiasm continues at a high level for those who choose to depart the topic at this point. But as time goes on it appears strategically prudent to examine “the rest of the story”.

### **Concerns from the Experts**

Over the past several months, Dr. Bruce Cheson, one of the most prominent lymphoma specialists in the world, has expressed concerns regarding rituximab. In his latest paper, *“Rituximab for Follicular Lymphoma: Maintaining an Open Mind”*, he comments, quote:

*“New data from the Primary Rituximab and Maintenance study provide the strongest support for the use of rituximab maintenance in patients with follicular lymphoma. However, further considerations of cost, inconvenience, toxic effects, efficacy of retreatment, and lack of survival benefit should focus future clinical research on more-effective induction strategies”.*

See <http://www.medscape.com/viewarticle/741155> (Free registration may be required).

We also note recent comments specific to MR from another medical specialist with no commercial ties to rituximab, in the prominent journal *Lancet*, quote:

*"The results of the important study by Gilles, Salles and colleagues do not seem to justify their conclusion that rituximab maintenance should now be considered as first-line treatment for patients with high-tumour-burden follicular lymphoma. In fact they suggest the opposite".*

See [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60459-5/fulltext?rss=yes](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60459-5/fulltext?rss=yes) (Note that there are response commentaries in the Lancet).

## **Personal Comments**

For many years, rituximab was regarded by virtually everyone as a positive advancement in managing fNHL...*(me included, at least on the treatment side of the ledger; otherwise I would not have taken it).*

Taken in total however, particularly in connection with MR, time and experience are beginning to raise some legitimate concerns, as summarized below:

**1.1 When rituximab is used in conjunction with chemotherapy**, the time to relapse is extended but an increase in **\*overall survival\*** has yet to be proven. Many have jumped to the conclusion that an increase in "progression-free survival" automatically results in an increase in overall survival, but this is not necessarily the case.

### **Key Points in Definition:**

1. "Overall Survival" (OS) time is just what the name implies, but (generally unknown), it usually includes death from any cause. 'Disease specific overall survival' refers to confirmed death due the disease.

2. "Progression Free Survival" (PFS) time is a recently created term resulting in confusion among patients and frequently in media coverage. Many people associate it incorrectly with length of overall survival. In fact, PFS measures the length of time that a patient is both alive and without worsening of their cancer.

Since it takes a very long time (at least 10 years and more like 15) to prove anything in connection with OS for fNHL, convenient short-term **\*endpoints\*** have been chosen in trials. For example, in trials testing maintenance rituximab the endpoint in most cases has been chosen as the length of time

for which patients become resistant to the drug, which is usually prior to four years.

1.2 **When used on its own as initial therapy**, upwards of a third of patients have **no response** to rituximab. *(One might wonder whether this group derives much benefit from any application of rituximab including with chemo or as maintenance. No one has ever chosen to test patients prior to administration of rituximab in a routine setting).*

1.3 Similar to virtually all drugs (seen as “foreign” invaders by the body), most people become **resistant** to rituximab when taken as MR in 4 years or less.

1.4 No one knows the degree to which this resistance will impede/block the **effectiveness of chemo if/when needed at a later date**. This is an especially important consideration in connection with treating probable **transformation**...the main barrier to extended survival...at which point it is critically important to have as few “inbuilt” impediments as possible to ensure a complete response, and optimize the chemo response as much as possible. Unfortunately, failure to achieve a complete response against transformation results in a very poor outlook. Dr. Cheson notes this concern with “re-treatment”.

1.5 Prior to resistance setting in, patients on MR exhibit some **decrease in the probability of relapse** (extended progression-free survival), however in every study so far conducted there has been **no statistically proven increase in overall survival due to maintenance rituximab**. Furthermore, after 4~5 years there appears to be an **\*accelerated relapse rate\*** such that those who took MR have no advantage over those that did not.

We still await results from the highly publicized **RESORT study** (Rituximab Extended Schedule or Re-Treatment) trial. Overall survival results from this trial will be a **“game-changer”** regarding the future of MR.

1.6 The serious matter of probable **infection** with rituximab is finally being openly acknowledged by the experts. This risk arises from the fact that rituximab **attacks normal immune cells** as well as lymphoma cells. Dr. Haines emphasizes the significance of infection along with no advantages in the quality of life when on MR. Dr. Cheson also notes the risk of infection, including the small risk of death.

Beyond that, we note the frequent connection between lowered **immunoglobulins** (Ig...immune antibodies required to fight infection) and

rituximab, although it is not clear whether sustained low Ig counts are due to the lymphoma alone, or to rituximab, or both. The risk appears to be higher with MR than when rituximab is combined with a standard chemo for a period not usually exceeding 18 weeks.

Once suppressed, it is very difficult to return Ig levels to normal/stable.

As a result, we strongly suggest that all patients have their Ig levels checked prior to (optional) MR. Furthermore, we also note references to the significance/risk of **hepatitis B** and rituximab and so a relatively simple blood test for both Ig and hepB should precede a decision to opt for MR.

Oral **colostrum** (from most health food stores) over a long period may help raise Ig levels, but reliable evidence (due to this alone) is absent.

1.7 Then there is the matter of **cost**. Patients often think of someone else paying, like the government or insurance company, but really no matter the system, it's really *\*society\** as a whole that foots the bill. Most governments today are seriously in debt. It seems obvious that no government in the western world will be able to sustain the anticipated cost of high priced drugs for an aging population. Serious economic cutbacks are inevitable.

In the case of rituximab the cost is far higher than anything else on the shelf...a standard 6 infusions running to well over \$15, 000 for the drug alone not taking into account direct "labor" costs of administration and assessment.

1.8 On the **opinion** front, would I still recommend rituximab you ask?

**Yes**, in conjunction with a standard chemo protocol, especially if it was for transformation. Nooo compromises allowed there.

**Maybe**, as initial therapy on its own (if available), but numerous assessment factors enter the picture here, all of which must be taken into account.

**No**, at least not if *\*optional\** MR is the plan.

Years of experience indicate that there is little merit in chasing incurable fNHL needlessly. Based on the expert opinions noted, the possible short-term decrease in the probability of relapse with no proven increase in overall survival with MR (likely for about 2/3 of the patients who respond to rituximab in the first place), do not offset the potential long-term downside that could persist for decades.

Periods of clinical remission should be utilized for “dynamic observation/active surveillance” to apply lifestyle strategies (now supported in the science of epigenetics) as outlined in Article #3 and the May 2011 newsletter to generate genetic remediation. We will probably never be able to prove the merits of this approach in terms of extended survival, but knowing the nature of fNHL, it seems like the most credible approach for the long haul, helping to hold things in check, perhaps leading to natural regression.

At all times, we **MUST** keep in mind that the **ONLY thing** so far proven to extend overall survival with fNHL is the patient’s immune microenvironment. Ways in which to support that fact form the basis for long-term success.

Fundamentally, it is prudent to set out a long-term 20++ year survival plan at the beginning with as much time in the thrive zone as possible, fully prepared to combat transformation from get-go. MR is not strategically comfortable in that role.

**That said**, it is well known that there is a distinct group of patients who feel they have to be “doing something”, frequently in response to advice from their relatives, caregivers and friends. See Article #1. For this group, short-term benefits in the first few years are the most important thing for now...maybe new drugs will show up in the meantime. For these patients, dynamic observation following the lifestyle strategies in Article #3 doesn’t cut it.

As people, we are very different, each one of us unique. The system must serve all. Ask the docs how easy that is!

In any event, for MR, be sure to get tested ahead of time for Ig levels and hepB as noted above in 1.6, optimal vitamin D as well.

1.9 Again, for those wanting to partake in dynamic observation, note that **certain supplements in Article #3 are NOT recommended while on MR**. Fundamentally, it’s not possible to be trying to kill cells with a toxic therapy while trying to generate overall wellness along with the natural, desirable death of cells at the same time.

1.10 In summary, rituximab is a controversial drug, especially when used in a maintenance setting. It is hoped that the information provided here will prove helpful when, as “general managers” of their case, members discuss rituximab with their medical professionals, weighing the pros and cons, always keeping in mind that each case is unique.

## **2. First Treatment...Two Options Outside the Box...with MD Support**

We are aware that many of our members are interested in credible treatments with minimal toxicity, especially as their first treatment.

In fact, we are pleased to report that there are now plausible, scientifically-based, medically-backed treatment options available. They offer a reasonable expectation of effectiveness with comparatively low toxicity...and I suspect low cost relative to other approaches. And they don't burn future treatment options, which is a consideration of great importance in managing fNHL long-term. As we say, keep your powder dry. Always have the potent "ammo" ready against the probable event of transformation.

Last month we reported on the work of Dr. Kirschbaum at City of Hope hospital in California into the application of epigenetics specifically to fNHL patients. Results of this work can be seen at <http://www.ncbi.nlm.nih.gov/pubmed?term=21300924>

Those interested should also read his interview comments in the May 2011 newsletter. Note also from the research report that the patient group, although understandably small in number with only 17 with fNHL, the overall response rate (ORR) was an impressive 47% (see personal comments below) with 4 complete responders, and significantly, these patients were relapsed/refractory, known to be a challenging group to treat...NOT utilizing this approach as their first treatment.

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We note another approach underway, although not specifically epigenetic, where the doctor prescribes the drug DCA for a wide range of cancers, including lymphoma.

DCA (dichloroacetate) is an inexpensive, common drug that has been much in the news over the last few years following a discovery at the U. of Alberta showing unexpected cancer fighting properties. Understandably, the drug attracted attention and with it predictable controversy. See our Topic Index for earlier coverage.

A reasonably balanced assessment of DCA can be seen in the New Scientist journal at <http://www.newscientist.com/article/dn10971>

DCA is believed to interact with a cancer cell's mitochondria (energy center), removing the cell's reliance on sugar for its survival (glycolysis) and hence its immortality. The mitochondria is activated and in doing so the cancer cell (gradually) takes on more normal respiration, glycolysis subsides, and the cell in time dies a natural death (apoptosis), as all normal cells are supposed to do. This theory parallels the work of Dr. Otto Warburg who won the Nobel Prize for his work in 1932, but the theory was never pursued as more (financially) attractive cancer fighting remedies became available.

If this sounds familiar, it is, since this is the same mitochondrial mechanism of action we are implementing with the **trans-resveratrol** as part of our "multitudinous crossfire" approach.

DCA is available at the **Medicor Clinic** where the patient could expect to receive qualified medical guidance and follow up. See <http://www.medicorcancer.com/index.html>

We first covered this clinic in the September 2008 newsletter. I have recently been in touch with Dr. Khan. He assures me the clinic is active and that there is updated information on the site re DCA at <http://www.medicorcancer.com/dca-data.html> (*We have no affiliation with this clinic or any other service*).

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#### Personal Comments:

OK, so what have we got here? In fact; there are two significant options/opportunities for fNHL patients.

Even though "first treatment" is noted in the title of this item, in the case of Dr. Kirschbaum's approach, his fNHL patients were relapsed/refractory. Those taking this treatment as their first one would most likely have a much higher response rate than 47%.

But that's not all...and here's the "clincher" to this entire item.

What if a patient were to take this conventional epigenetic treatment offered by Dr. Kirschbaum to (hopefully/fully) open up the DNA access AND ALSO adopted the natural lifestyle strategies we have suggested here based on parallel scientific studies. Hmmm?

To some extent, the same approach could be taken with Dr. Khan at Medicor, although DCA's action is not primarily epigenetic.

Perhaps it's not unreasonable, where practical, to combine Dr. Kirschbaum and Dr. Khan?

To those for whom this item has relevance, give it some thought. If you decide to pursue one or other of the options...maybe even both...for the benefit of us all, please keep us posted on our discussion board.

We won't win the game and achieve the "thrive zone" with permanence by following old, well-worn ruts inside the box.

### **3. A Tale of Two Organs...the Bowel and the Brain Connected**



Image...Scientific American Feb. 2010

The bowel is an exceedingly important organ governing basic good health.

The reason for covering this is because bowel distress is very common among lymphoma patients.

It is not surprising that the *human intestine is surrounded by numerous lymph nodes*. Lymphomas may originate in this location and remain there for some time, perhaps years, before becoming problematic or showing up elsewhere.

In some cases, problem nodes can grow to a large size and push on the bowel. It is possible for lymphoma nodes to encompass the bowel and block it off. Where this is suspected, the problem needs to be checked out.

Commonly however, and fortunately, what often has happened arises from one specialist stated, that is; **"the bowel does not like company"**. The inference here is that the mere presence of abnormal cells adjacent to the extremely thin one cell bowel lining (epithelium referred to above) is sufficient for the bowel to go into spasm, resulting in symptoms akin to a blockage.

As mentioned above, almost all adults have bowel issues, increasingly with age. However, **it seems as if the problems are more frequent and more acute with lymphoma patients than in the general population.**

### 3.1.1 Some Basic Facts About a Very Complex Organ:

> The human bowel contains about *100 trillion cells, 10 times more than all those in the rest of the body put together* (an even greater number than the national debt!).

> There are approximately *500 bacterial sub-types. Some have yet to be identified.*

> *Some bacterial sub-types are "good" and a few are "bad".* A normal bowel flora has both (but the bad ones are limited and held in check).

> The total weight of just the bacteria in the bowel is about *three pounds.*

> The bowel digests food, produces vitamins, regulates hormones, excretes toxins and produces healing compounds to keep one healthy. Some references state that *bowel function constitutes 70% of the body's immune system.* As such, it's just as important in regulating one's immunity as is the lymphatic system. In fact, as would be expected, they work (or should work) as a team.

> Just as there are four different blood human types it has now been found that there are *three (at least) distinct categories of intestinal bacteria.* Thus, not all people digest fiber, produce vitamins and enzymes, or process drugs the same way. No account has ever been made for this individual variation in the past.

> The body is protected from the toxic environment of the gut by a *layer of cells only one cell thick known as the epithelium.*

> The epithelium has an enormous *surface area for absorption, equivalent to the area of a tennis court!*

> A break in the epithelium results in "*leaky gut syndrome*", what the doctors refer to as "*increased intestinal permeability*". If/when this barrier is damaged, sickness results, the immune system becomes overactive, and produces cancer causing inflammation throughout the body.

> The bowel has its own nervous system which functions literally as a "*second brain*" in the body with *more neurotransmitters than the brain in one's head*.

> There is a *direct "communications link"*, called the *vagus nerve*, linking the *gut to the brain*. Ninety percent of the fibers in this nerve carry information from the gut TO the brain, not the other way around. Thus, a big part of our emotions are influenced by our gut. There may be more to the expression "*gut reaction*" than first thought.

> Virtually all *serotonin* in the body, usually thought of as a brain chemical known to influence mood control, depression and aggression, is found *in the intestines*, not the brain! Thus the bowel plays a significant role in one's sense of "*well being*", and likely at least some forms of transitory depression.

> Some researchers believe that the brain/bowel connection and gastro intestinal dysfunction are related to childhood *autism* and perhaps ADHD. There has also been speculation regarding bacterial genes incorrectly switched on or off resulting in obesity and colon cancer.

### 3.1.2 Optimizing Bowel Function

After taking in all the above points, some of which may be surprising to many people, it should now be apparent that the bowel plays a major role in both physical and mental health. It's the "***inner tube of life***" in more ways than one.

In addition, because of its prominence in regulating immunity, it clearly plays an important role in the management of lymphoma as an immune system cancer.

Soo, how are we going to make use of all this information? Clearly, with the many complex factors mentioned above, all working at the same time, there is no single or magic answer to stable, essential bowel function, as most of us know especially as we age, from time to time experiencing irregular function.

The following points should help in optimizing bowel function:

- A first approach that seems to work well for many people is to restrict **sugar** intake. This causes the good bacteria to flourish, crowding out the bad bacteria, a process which may take a few days. A problematic *fungus/yeast balance* will also be reduced. **Flour**, like sugar, is a rapidly digested carbohydrate that stimulates activity of bad bacteria. As people age, they usually have a harder time digesting carbohydrates. Many people regularly restrict/eliminate all foods with flour with good results. **Alcohol** acts in a similar way to sugar.
- Some people have **gluten intolerance** (celiac disease) which, in simple terms, is a bowel reaction (often severe) to wheat, rye, barley and sometimes oats. Many are unaware of the condition, having learned to “live with” the disorder and the ongoing discomfort it creates.
- **Antibiotic drugs** are virtually certain to de-regulate optimal bowel function. When taking an antibiotic, many pharmacists recommend corresponding **probiotics** be taken at the same time to replace the good bacteria killed off by the antibiotic. Probiotics are beneficial bacteria. They are usually taken for some time after completion of antibiotics to help restore normal bacterial balance. **Purchase quality adult probiotics from the refrigerator section in the health food store.** Natural **yogurt** (preferably “full fat organic”) is a common food rich in probiotics. Note, however, that some people are *lactose intolerant*, lactose being a type of milk sugar. (More detail in Article #3, where *calcium* in the yogurt is utilized for absorption of *vitamin D* and the *fat* is required to pre-dissolve the curcumin, which also is believed to stimulate immune function in the bowel). Some people take a probiotic supplement on a regular basis. Confirmation of how probiotics stimulate immunity can be seen at <http://www.ncbi.nlm.nih.gov/pubmed/16633128>
- **Fiber** is essential in the diet to enable good bacteria to form short chain fatty acids that are absorbed into the bloodstream and travel to the liver where they block the liver from making too much *cholesterol*. (The liver makes about 80% of the cholesterol in the body). This process also reduces *inflammation* to help ease joint pain and numerous other problems known to be associated with inflammation.
- Like fiber, **prebiotics**, are non-digestible food ingredients known to play an essential role in driving the growth of “friendly” bowel bacteria. Prebiotics are in beans, seeds, vegetables and nuts. **Prebiotic vegetables are predominately green.** *The Brussels sprouts (Article #3) are a wonderful way to get the day started off with prebiotics,*

*resulting in a "happy" bowel...as well as in opening up the DNA for healthy genetic action to take place.*

- Although subject to over-simplification, constipation points to the need for more fiber and fluids in the diet, along with **regular exercise** (such as brisk walking) whereas an over active bowel (and certainly diarrhea) suggests an imbalance in good/bad bacteria, a fungal/bacterial imbalance, or the presence of certain types of bad bacteria that can be serious such as *E. Coli* or *C. Difficile* which is serious and may be acquired while in hospital. **Wash hands frequently.**
- Over-eating can upset the bowel, creating a stressful situation whereby the bowel is impaired in doing its huge multitude of tasks properly.
- Bowel cleanses, "hydrotherapy", enemas and the like are often commercially motivated, are controversial at best and are likely to upset the important and delicate functioning of those three pounds of "correct" bacteria in the bowel...ultimately with the potential of doing more harm than good.
- **Mental stress** is a well known and potent cause of bowel distress...rather obvious taking into account the direct linkage between the bowel and brain as described above. Accordingly, some people may benefit from stress reduction/relaxation strategies such as **meditation, music...in fact any enjoyable activity** that results in a \*healthy\* departure from what appears to be causing the problem.
- **Strenuous high impact sports** such as (competitive) distance running are well known to cause an over-active bowel...AND result in dangerous bowel leakage and overload on the lymphatic system (*which in this case is called upon to function extra hard as the body's biological "sewer" system*).
- **Chlorine** is a powerful "sanitizing chemical". Thus, chlorinated tap water (in almost all localities nowadays) could plausibly be linked to a reduction in good bacteria.
- The (highly) recommended "first thing in the morning" **ginger** drink in Article #3, although directed primarily at controlling excess bacteria *H. Pylori* in the stomach, and then leading to efficient digestion of anticancer nutrients in the recommended breakfast, is also a good "primer" for optimal bowel function.

- In cases where a \*fungal\* overgrowth is suspected (which may be indicated by excessive gas and possible bloating), **oil of oregano** drops taken orally on a regular basis for several days may help temporarily.
- **Oral digestive enzymes** are often recommended by misinformed individuals or those motivated by commercial incentive. Some foods contain enzymes, but fact is, the body produces most of its own digestive enzymes primarily in saliva, the stomach, pancreas and bowel. Oral enzyme supplements are of dubious value since they become neutralized by strong stomach acids before reaching their intended destination even when enterically coated.

### 3.1.3 Medical Surveillance

Bowel problems of an unusual nature, and there are many of them, should be checked with one's medical team. It is an important priority to monitor lymphoma in the bowel area (and kidney region as well) \*regularly\*. The ONLY way to do this with reasonable accuracy is with a CT scan. Unless a problem is perceived, a PET scan (with its additional radiation) may not be warranted. Radiation accumulation over the 20++year planning horizon we support here remains of some concern, but knowing the status of lymphoma in the bowel and kidney region is the more important consideration in being able to take early remedial action when/if necessary.

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Although the notion of a "second brain" is somewhat misleading, it's perhaps useful to think of the bowel as the primary organ in the body that "sets the tone" for numerous important body functions to follow, including mental function.

Hopefully, this extensive focused coverage has been both instructive and potentially helpful. **As goes a smoothly operating bowel, so goes the successful management of fNHL.**

Reference data from:

<http://www.scientificamerican.com/article.cfm?id=gut-second-brain>  
<http://www.medicalnewstoday.com/releases/223032.php>  
[http://www.ehow.com/info\\_7911588\\_vegetables-prebiotics.html](http://www.ehow.com/info_7911588_vegetables-prebiotics.html)  
<http://www.experienliefemag.com/issues/september-2008/wellness/functional-wellness-part-3-digestive-health.php>

## **4. False Positive Scans**

From Cornell University, April 2011...quote:

*"A recent study published in the journal Leukemia & Lymphoma found that only 21% of positive surveillance PET/CT scans represented actual relapse; i.e., 79% of (lymphoma) patients with scans that were read as positive had not relapsed. Patients with false-positive scans therefore underwent additional scanning and invasive biopsies with no benefit. Moreover, the scans added over \$8000 per patient to the cost of follow up."*

Personal Comment:

*(Note that a "false positive" refers to identification of a problem or concern that is not actually present).*

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In past newsletters (see our Topic Index) and mentioned in the previous item, concerns have been expressed regarding the accuracy of PET scans (on their own) for fNHL patients. The issue is a serious one taking into account the accumulated radiation exposure from scans and subsequent risk from secondary cancers in later years, particularly as an inherent feature of a long-term plan for the responsible management of a patient over many years of potential survival.

Thankfully, this data has now surfaced from a reliable source. The findings are surprising. Some might suggest stronger wording, especially where incorrect data arises about 80% of the time suggesting that a patient has a "problem" when in reality there is none and the data has possibly been used as the basis for (unjustified) treatment. Mental anguish and cost are clearly significant factors as well.

On a supportive note, it would seem plausible that there are cases where a combined CT/PET scan is warranted, particularly when the lymphoma is small but in a problematic location AND the data from one can be "overlaid" on top of the other to help validate the results.

Also, there may be justification for a PET scan on its own when following up on treatment for transformation.

The take home point here is clearly that fNHL patients should question what may appear to be the \*routine\* use of combined CT/PET scans with their doctor, particularly the additional PET. Copy the Cornell data as a basis for discussion. Be particularly wary of situations where the doctor is allowed to have (joint) ownership of the scanner(s). Note also, that it may be questionable to proceed with treatment on the basis of scan results alone. There are usually many other important factors with fNHL to take into account.

For what it's worth, I have never had a PET scan, and likely never will have one.

See

<http://cornell-lymphoma.com/2011/04/28/lymphoma-in-the-news-routine-surveillance-petct-scans-prone-to-false-positives/>

## **5. Doctor Consultation**

Members often express concern with the medical care they are receiving. This is not always the fault of the doctor(s), especially for something as uncertain and controversial as fNHL. Thus, second opinions are very common in the case of fNHL, and in fact are frequently welcomed by the best doctors.

We try to help members as best we can in locating highly rated specialists. One such recent example was the item "Doctors Helping Doctors" in the September 2010 newsletter.

Unfortunately, a doctor in Seattle who has been very helpful in recent years guiding several of our members who visited him will be retiring soon and is no longer able to accept patients. He did, however, provide us with the name of another doctor in his clinic. Please contact me by email at [Robert@lymphomasurvival.com](mailto:Robert@lymphomasurvival.com) for more information on this. Or if you wish, check our discussion board under the topic "Specialist in Seattle" and my posting of April 25, 2011.

Lately, we have also established contact with a prominent specialist in the east who is receptive to consultation with our members. Again, please contact me by email.

## **6. 57% Lower Risk of Cancer Progression**

Here is yet another study (from May 2011) showing the benefits of regular exercise in the successful management of cancer. This study, although on prostate cancer patients (over 1400), could reasonably be expected to be applicable to those with fNHL suitable for clinical observation.

There are many clinical parallels between early stage low PSA prostate cancer where patients are usually not treated but followed instead with "active surveillance", and non-symptomatic fNHL patients managed in what

we call "dynamic observation". A variety of healthy lifestyle strategies likely produce favorable epigenetic benefits for both groups.

Note earlier coverage from our Topic Index covering exercise applicable to lymphoma.

Note also in this study that there was a benefit in \*brisk" walking (3 mph or faster) as compared to something more leisurely that might simulate walking the hound.

Note further that if any new drug had even near this (epigenetic) potential leading to proven results, it would be hailed world-wide immediately as a breakthrough...probably with more marketing promotion than this article received, and many others like it.

See <http://www.cancercompass.com/cancer-news/article/36917.htm?c=NL20110525>

## **7. Rhythm of the Mitochondria**

Somewhat akin to the last item, it's been said that hiking does more than transport us, it transforms us. (*"Heading Outdoors Eventually Leads Within"*, by Kathy and Craig Copeland, 2011 [www.hikingcamping.com](http://www.hikingcamping.com) ). We find it leads to calmness, detachment and clarity of thought.

On a personal note, one such thought is, *"how come all organs of the body are prone to cancer, except one (in which it is very rare)?"* That organ is the heart.

It would be nice to attach a romantic connection to this fact, and maybe there is some basis for that, but the practical aspect of the question suggests the intriguing, plausible answer that it's the huge number of mitochondria in the heart's muscle cells that blocks malignant growth.

Mitochondria, the "energy centers" of the cell, are contained in large numbers, not surprisingly in muscle tissue, including the heart. Interestingly they have their own unique DNA distinct from that in cells in other parts of the body, and are inherited entirely from the mother.

The relationship between mitochondria and cancer is as active area in medical science as a google or bing search will indicate.

Mitochondria are strange, intriguing characters, likely with a lot of hidden secrets.

At any rate, this thought brings us back to item #2 above. Could this be "where the gold is buried", as Nobel Prize winning Dr. Warburg thought? Amidst all the endorphins, MAYBE! As a bonus, a few nuggets follow.

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**8. Nuggets in the Pan** (*Astaxanthin; The "Full Meal Deal"; Diet, Cancer and the NCI; Latest Pharmaceutical Research Backs Our Suggestions; Good Curcumin/Bad Curcumin; Red Palm Oil and Cholesterol; Key Limitation of Many New Drug Therapies; Epigenetics Update Video*)

**\* Astaxanthin**

Here's an interesting compound, which although not being suggested as a new addition to the exclusive "A-Team" of supplements in Article #3, has what appears to be some beneficial properties. Remember that positive epigenetic benefits come from a very wide range of lifestyle factors in the \*total\* environment (influencing methylation...see the video in the last nugget below.

Check out the video at <http://www.healthiertalk.com/what-astaxanthin>

**\* The "Full Meal Deal"**

These familiar words don't imply overeating. Rather, they refer to the importance of the interrelationship (synergy) between various supplements and food groups in Article #3. Examples are:

- **Calcium in the yogurt and the absorption of vitamin D**, whether from the sun or by supplementation. In turn, the calcium must be accompanied by the **magnesium** supplement. So it's a mandatory chain of "events". Leave out one part and others will not work well, if at all.
- **Selenium and red palm oil** with its full spectrum of vitamin E (tocopherols AND tocotrienols). Selenium appears to work best when in combination with other nutrients which number in the hundreds in real food.
- **Resveratrol and exercise**. Resveratrol, as noted frequently, stimulates the mitochondria, and so does exercise. 1+1=3. Add the **raspberries** for a multitude of nutrient, anticancer benefits ...and a little iron in conjunction with the exercise to optimize blood hemoglobin.

It is beneficial for each person to create his or her own plan when it comes to diet, supplements, in fact, all lifestyle strategies, but there are

important interrelationships that should be noted where one thing needs to be in combination with others.

### \* Diet, Cancer and the NCI

The National Cancer Institute is seen by many as the bastion for sober, conservative thought when it comes to natural strategies and their possible connection to (successful) cancer management. Over the years, many people have noted what appears to them as bias against such strategies.

Be that as it may, here's a recent PubMed article from 2010. The article is (predictably) extremely cautious and tentative, but at least note the reference to epigenetics.

<http://www.ncbi.nlm.nih.gov/pubmed/21403607>

### \* Latest Pharmaceutical Research Backs Our Suggestions

Wow, look at this **nugget**. You won't see too many sites singling out the merits of sulforaphane and resveratrol exclusively, but you'll see 'em here and have done so for a few months in Article #3 and the May 2011 newsletter.

<http://www.ncbi.nlm.nih.gov/pubmed/21466425>

### \* Good Curcumin/Bad Curcumin

Over the last few years, curcumin has gained a lot of publicity, mainly as an anti-inflammatory. As a result, similar to resveratrol, numerous suppliers have sprung up in many countries. Some have even taken into account that almost no curcumin actually has sustained bioavailability in the blood unless pre-dissolved in a fat or oil, and so (like vitamin D) some suppliers now market it in an oil base.

Again, we recommend pre-dissolving it in full fat yogurt...which as noted also has other vital roles.

With its current market appeal, curcumin...or so-called curcumin, is found in a variety of forms. The cheap ones are probably primarily turmeric powder with likely less than 10% actual curcumin, which is the active ingredient. Check the label to verify that it has \*95% curcuminoids\*. Watch for trick wording. It's probably also the case the real curcumin will

NOT be grainy when dissolved in the yogurt, and that it be a bright orange color, not a tan shade.

#### \* Red Palm Oil and Cholesterol

Countries with the highest palm oil intakes in the world are Costa Rica and Malaysia. Their heart disease rates and serum cholesterol levels are much lower than in western nations. This never was a real health issue.

<http://www.drmirkin.com/nutrition/8621.html>

#### \* Key Limitation of Many New Drug Therapies

Most (recent, non-chemo) drug development has been directed toward specific molecular targets. However, the result of these specific treatments is eventual cancer relapse. One interpretation of this is that (cancer) is regulated by **several signaling pathways**. Therefore, inhibition of a single key pathway does not inhibit the many ways in which cancer cells survive and propagate. Resistance should be prevented by targeting (ALL cancer) pathways. And finally the last nugget (which was featured earlier), offers invaluable insight into where the gold is really buried.

#### \* Epigenetics Update Video

[http://www.teachersdomain.org/asset/biot09\\_vid\\_epigenetics/](http://www.teachersdomain.org/asset/biot09_vid_epigenetics/)

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Finally, here are some recent photos from along the trail I hope you enjoy.





Best in Health, Everyone,

Robert

June 2011

<http://www.LymphomaSurvival.com>

*Strive* >> *Survive* >> *Thrive*

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