

Immune Deficiency Foundation

# Patient & Family Handbook

For Primary Immunodeficiency Diseases

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## Chapter 33

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*6th Edition*

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## Chapter 33

# Supplemental, Complementary, and Alternative Medicine in Primary Immunodeficiency

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*Complementary and alternative medicine (CAM) has been gaining popularity in Western culture as the list of conventional therapies for primary immunodeficiency diseases (PI) is limited relative to other medical conditions. Benefits and risks of these kinds of therapies are mostly anecdotal or theoretical, with little to no well-designed clinical trials existing to support their use. Use of these kinds of therapies should be discussed with an individual's healthcare provider. It must be remembered that they are to be used as complementary—in addition to, not as an alternative to conventional medicine.*

## Introduction

There are over 350 different types of PI that interfere with the body's immune system. These deficiencies can be attributed to the improper functioning or absence of a required component of the immune system. Medications offered by your health care provider are frequently aimed at enhancing the protection against infections that occur in these immune deficiencies. Depending on the type of PI a person has, medications may be part of everyday treatment. For example, people with Chronic Granulomatous Disease (CGD) take protective antifungal and antibacterial medications every day. People with some antibody disorders, like X-linked Agammaglobulinemia (XLA), require immunoglobulin (Ig) replacement therapy. In the US, the Food and Drug Administration (FDA) requires that all prescribed medications be rigorously tested before they are approved for use. This process often requires years of research and development. But once approved, this process allows the prescriber to understand the risks and benefits of the drugs, and they can then prescribe them based on this understanding, what is called evidence-based decision making.

CAM therapeutic modalities, such as Traditional Chinese Medicine (TCM), Ayurvedic medicine, acupuncture, yoga, chiropractic medicine, and massage therapy, continue to gain widespread popularity in the U.S. and throughout the global economy due to their perceptive impact on immune health. CAM is viewed as a group of diverse medical and health care systems, practices, and products that are not generally considered part of the conventional allopathic (Western) medical practices. Complementary medicine commonly signifies "in addition to" rather than "a substitute for" clinical interventions used with conventional allopathic medicine. On the other hand, alternative medicine is occasionally used in place of conventional medicine. This is a distinction reflected by the National Institutes of Health—National Center for Complementary and Alternative Medicine (NCCAM).

The use of CAM is gaining interest in Western countries because of its reputed effectiveness, low cost, and favorable safety profiles. People are often interested in CAM therapy for chronic conditions either because they are unsatisfied with conventional therapies or because they have



concerns regarding side effects of synthetic drugs. Here, the use of supplements as part of CAM therapies will be addressed.

## Supplements

Supplements are part of CAM therapies. They include vitamins, herbals, pro-biotics, and fish oils. It is important to recognize that supplements are not held to the same standard as conventional medicines. They are not regulated by the FDA. Accurate and reliable information on different supplements is hard to find, and recommendations are often based on personal beliefs and experiences rather than evidence obtained from well-designed studies as with conventional medicines. For this reason, all of the different ways in which a supplement acts on the body is often not known. Although some products are thought to stimulate the immune system based on observations in healthy volunteers or in animal studies, it is not known if the desired effects will be seen in people with PI. It is also not known what the supplements effect will be on other drugs an individual may be taking or other diseases a person might have.

Daily multivitamins are marketed as a way to ensure one gets all the minerals and vitamins needed to remain healthy. Daily supplementation is often excessive as most people get all the vitamins and minerals they need from their diet. Short of the cost, there is often no harm in taking one or two of these a day. However, there is no literature to suggest daily supplementation with a multivitamin improves immune function in people with PI. Vitamin A (retinol), vitamin B6 (pyroxidine/pyridoxal phosphate), and vitamin E are naturally found in many foods and are thought to play a vital role in supporting a healthy immune system. However, there are no studies to suggest there is any benefit to excess supplementation in people with PI.

Additional supplements include L-arginine and zinc. L-arginine is a building block (called an amino acid) that is needed to make proteins in your body. A person gets it from eating red meat, fish, poultry, and dairy. There are conflicting studies regarding whether or not taking L-arginine stimulates immune function in people with secondary immunodeficiencies (such as HIV). However at this time there are no studies suggesting it may be beneficial in people with PI. Zinc is a mineral that is involved in many physiologic processes in the body. There is debate regarding whether or not supplementation is beneficial or harmful in people with secondary

immunodeficiencies. However, there are no studies that look at the effect of excess zinc supplementation on immune function in individuals with PI.

Herbal supplements are plants used in traditional healing practices that are believed to have medicinal properties. Their proposed benefits are often well advertised despite not being backed by evidence gathered from well-designed clinical trials. Complicating the studies that do exist are questions regarding herbal potency and quality (chemical content). For example, how much does the strength of a supplement vary from pill to pill? Unfortunately, the possible harms are not typically advertised as manufacturers are not required to do so. Reporting of adverse effects linked to supplements is voluntary and very difficult to prove. For example, there are no standard lab tests for herbal blood levels a doctor can order. Thus there is very little known about how these supplements interact with drugs and diseases.

There are many herbs that are currently advertised as able to boost immunity. These include astragalus, ashwagandha, cat's claw, echinacea, goldenseal, and European mistletoe. There is presently no research to support their use in people with PI. However, they are often well tolerated when used in small amounts. It is important to know there are no studies on optimal dosing. This is important because some supplements, such as astragalus, may cause immunosuppression in larger doses.

Fish oil, obtained by supplements or by eating fish, contains fatty acids that have been shown to lower triglyceride levels. Fish oil is typically tolerated well, with common side effects being belching and odorous breath. However, like astragalus, there is some data to suggest mega doses of fish oil may cause suppression of the immune system.

A growing trend over the past decade has been the supplementation of probiotics. The idea is that the human gastrointestinal tract is made up of hundreds/ thousands of strains of known bacteria and some unknown that all compete for nutrients and space to grow. "Good" bacteria help with tasks ranging from the breakdown of food to preventing bad bacteria from making a home in the gastrointestinal tract. Probiotics are bacteria that are considered beneficial to their host. Some foods, such as yogurt and cheese, naturally contain these bacteria. Probiotics have been well-studied for certain allergic and infectious indications, and have been found useful in preventing antibiotic-associated diarrhea. However, they have been implicated in severe bloodstream infections in individuals with inflammatory bowel

disease. Although the bacteria used in probiotic supplements are considered to be safe, theoretical concerns have been proposed regarding probiotic safety in people with PI. There are a few case reports where probiotics have harmed individuals with PI.

## Conclusion

When considering supplement use, it is important to remember that most have not been studied as being possible therapeutic options for people with PI. Some products may have absolutely no clinical evidence behind them and their proposed benefit to the immune system is theorized based on laboratory observations. Risks of supplement-drug and supplement-disease interactions are for the most part unknown. High-quality studies are needed to better understand the risks and benefits of using these products. It is important to remember that these interventions are at the very most complementary and not alternative because they should be used with, not in the absence of, modern medicine. If you wish to incorporate CAM into your care, it is important to first speak with a physician to determine if and which CAM is right for you.


## References

- Bielory L Complementary and Alternative Medicine in Allergy-Immunology: More Information is Needed. J Allergy Clin Immunol Pract. 2018 Jan - Feb;6(1):99-100.

# Supplements Summary

## Table 33:1

Integrative Therapy	Vitamins	Herbals	Probiotics	Fish Oil
<b>Products Advertised as Beneficial</b>	Daily Multivitamin, $\beta$ -Carotene, L-Arginine, Vitamin A, Vitamin B6, Vitamin E, Zinc	Astragalus, Ashwagandha, Cat's Claw, Echinacea, Ginseng, Goldenseal, European Mistletoe	Probiotics	Fish Oil
<b>Overview of Risks</b>	Very little risk of physical harm. However, supplementation with vitamins and minerals is often unnecessary in individuals with immunodeficiencies.	Potential for harm is often theoretical. Supplement-disease and supplement-drug interactions are based on theoretical mechanisms of action supported by limited research. Additionally, different studies may use different types of plants and different methods of preparing the herb. Risk is highlighted by plants such as Astragalus, which may suppress the immune system in larger doses.	Potential for harm is theoretical. Severe bloodstream infections attributed to these bacteria have been found in individuals with irritable bowel disease, showing potential to be of a risk. No literature exists examining this risk in immunocompromised individuals. Also, there is no equivalence between probiotics – even of the same species.	Potential for harm is theoretical. Avoid consuming greater than 3 grams of fish oil supplements daily as it may lead to suppression of the immune system.
<b>Overview of Benefits</b>	Insufficient evidence to support claims that excess supplementation benefits people with primary immunodeficiencies.	Insufficient evidence to support claims that supplementing with these herbs benefits people with primary immunodeficiencies.	Insufficient evidence to support claims that supplementing with probiotics benefits people with immunodeficiencies.	Insufficient evidence to support claims fish oil supplements benefit people with immunodeficiencies.



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