



# **FACT SHEET**

# DELUSORY PARASITOSIS. THE BELIEF OF BEING LIVED ON BY ARTHROPODS OR OTHER ORGANISMS.

# Guide for Health Departments, Medical Communities, and Pest Management Professionals

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#### Introduction

Delusory parasitosis, an unshakable belief or syndrome (Hopkinson 1970) of being attacked by insects, is a very difficult and under-diagnosed condition. It often starts with an actual event or medical condition (the trigger) that may progress over time into mental illness. For those who have had the problem over long time periods, the condition can sometimes consume a person's life. Although patients may repeatedly seek help from experts, they may refuse to abandon their ideas for test results which contradict their invested beliefs (Sneddon 1983). Sufferers can become antagonistic and relentless in their need to find someone who will confirm their self-diagnoses (Murray and Ash 2004). Those with the obsession, often search the internet, finding web-sites that support their fears. Often under the falsehood of medical authority, some of these sites provide misguided advice and inaccurate information. Poorly informed misdiagnoses by medical professionals may also contribute to the problem. This is a very complex and difficult condition to manage, requiring dedication and time by trained professionals or an interdisciplinary team of experts.

# Naming the syndrome

Because delusory parasitosis (DP) is medically amorphous, several medical specialists have been involved, e.g., psychiatrists, physicians, dermatologists, and medical entomologists. All have tried to define the condition.

The term delusions of parasitosis was coined by Wilson and Miller (1946) dispelling earlier use of the words acarophobia (Thibierge 1894), entomophobia, and parasitophobia. These earlier words characterize a mental condition based on the concept of *fear*. Delusions of parasitosis characterize a *belief* of being lived on by arthropods. Waldron (1963) shortened the term to "delusory parasitosis", which Keh (1983) supported. The term is commonly used today, and is the name of choice for this fact sheet.

Delusory parasitosis, often called Ekbom syndrome (Hinkle 2010, Ekbom 1938, Koblenzer 1987), belongs to a group of disorders called Monosymptomatic Hypochondriacal Psychoses (Munro 1983, Reilly 1977, Bishop 1983), which include bodily disease and

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abnormality or physical alteration delusions (Reilly 1977). These conditions tend to be found in individuals with obsessive personality traits and/or relative social isolation.

The term Morgellons disease was adopted by a biologist-mother with affected children when a physician could not diagnose or treat their illness. The term was first used by an English physician, Sir Thomas Browne in the 1600's for children suffering from coughs and convulsions in France (Kellett 1935), but is now being used more narrowly for DP-like symptoms. It is controversial, prompting much discussion in the scientific community. In response to the controversy, a northern California study completed by the Centers for Disease Control and Prevention (CDC) aligned Morgellons with delusory parasitosis (Pearson et al. 2012).

Other names used for delusory parsitosis are matchbox and saran-wrap sign (reflecting how specimens are delivered to the analyst), paper mites, sand fleas, cable mites, presenile dermatozoic delusion (used widely in Europe), chronic tactile hallucinosis (Conrad et al. 1954), and folie à deux, "a madness shared by two" (Kim et al. 2003).

## The sensations of delusory parasitosis

Descriptions of what sufferers feel range from pricking, tingling, creeping, and crawling sensations to something burrowing through the skin (Hinkle 2000). Descriptions of insects living inside body openings and the alimentary canal are not uncommon. Many describe feelings of itchiness with a continuous need to scratch and/or report seeing actual arthropod specimens addressing them as "they" or "them". Self-mutilation is common (Hinkle 2010, Snedden 1983, Koo and Lebwohl 2001).



**Self-mutilation of the left hand (used with permission)** 

#### Some conditions which may trigger or cause delusory parasitosis

There are at least four types of conditions which may trigger DP: environmental; medical, including psychological (Koo and Lebwohl 2001); drug side effects; and commonly encountered insects and arachnids (spiders and mites).

#### **Environmental**

Static electricity. When there is low humidity, static electricity may be a problem, especially around fabric covered furniture and carpeting. This condition occurs in hospitals, climate-controlled office buildings, college/university dorms, buildings with steam heat, and buildings with closed ventilation systems. Conditions caused by these environments can cause skin sensations interpreted as something crawling on or "biting" the skin (Scott and Clinton 1967, Simpson 1987, Hinkle 2010).

**Pollen**. People who move from one region of the United States to another may experience allergies to local tree and grass pollen. This may manifest as unexplained irritation which is interpreted as apparent insect biting (Clark and Adinoff 1989, Cabon et al. 1996, Heiss et al. 1999).

*Household or personal products*. Detergents such as hand soaps, detergents (especially phosphate-based products), ammonia-based cleaners, cosmetics, hair products and house hold cleaners, some printer inks and clothing with fire retardant can cause dermatitis (Hinkle 2010).

*Mold.* Since Hurricane Katrina, mold has become a more closely studied problem in homes. Damp or water-damaged buildings often have mold. There are many species of household mold. Some mold and mold spores can be medically significant and can cause dermatitis. One of these is *Stachybotrys chartarum* (Atra), a black mold that thrives on water-damaged cellulose-rich materials, such as sheet rock, paper, ceiling tiles, insulation backing, and wall paper (Johanning et al. 1998, Clark and Adinoff 1989).

*Known irritants*. Formaldehyde impregnated products, such as particle board, floor tiles and wall coverings; some papers, insulation fibers and some man-made fabrics; cigarette and cigar smoke, and fresh asphalt are known to cause dermatitis (Vail 2006, Potter 1997).

#### Medical conditions and disease

Numerous medical conditions and diseases may cause DP (Table 1). Three of the most important causes are stress, depression, and aging (Hinkle 2000).

*Stress*, including post-traumatic stress syndrome (PTSD), is seen in all socioeconomic and educational levels, and is a major cause for DP. Stress-related DP often starts with a tragic or unpleasant episode at a specific time. This may be a divorce, separation, loss of employment, illness, a failure, death or illness of a relative or pet, witness to an incident, or war trauma. Other longer-term stressors are unrewarding employment, multitasking career and family, incessant media focus on bad news, money concerns, lack of sleep, and loneliness (Seville 1983).

Many sufferers of DP live alone and get into a habit of fixating on their health. It becomes a comfort, and allows them to garner often needed interaction from others.

Self-grooming is a strong societal force in people. As primates, humans touch, scratch and groom as forms of self-assurance and social interaction. It is reflective of social status, self-image and psychological well-being (Hinkle 2000). In situations of stress, including tension, worry, or anxiety, people often show "displacement activity" by scratching; they may for example, reach up and rub the neck, scratch the head or forearm after an unpleasant encounter. Delusory parasitosis sufferers often take this further by continuing the behavior. They usually are unwilling to accept the suggestion that the symptoms they experience may be associated with stress (Hinkle 2010).

**Depression**, is a second major contributor to DP (Koo and Lebwohl 2001). Anxiety, tension, tiredness, lack of interest in life, low self esteem and energy, a sense of displacement, feelings of guilt, worthlessness, and helplessness all may contribute to depression and DP onset. A DP sufferer with depression usually vehemently disagrees with the possibility of depression, so the problem often goes untreated. Schizophrenia also has been implicated as causative for DP (Hinkle 2010).

*Age.* Delusory parasitosis can appear at any time in adult life, but is more common later in life. Men and women are equally affected in the younger years. In those older than 50, there is a preponderance of women affected over that of men. However, men tend to suffer from DP at a younger age than women (Trabert 1996).

### Table 1. Some medical conditions associated with delusory parasitosis

Allergies including food allergies\* Hepatic disease\*
Hypertension\* Cirrhosis\*
Congestive heart failure\* Cholestasis\*

Menopause\* Carcinoma\*
Insect phobia Many cancers including Leukemia\*

Anemia\* Niacin overdose\*

Mental retardation (Koo 2001) Several autoimmune diseases including

Huntington's disease\* multiple sclerosis and Lupus\*

Hepatitis\* Poor nutrition\*

Hypovitaminosis including B12 Endocrine abnormalities\*

deficiency (Koo 2001) Hyper awareness of normal nerve end firing

thiamine deficiency\*
Hyperthyroidism\*
Hypothyroidism\*

Meningitis\*

Hypoglycemia\* Syphilis (Koo 2001)
Renal diseases\* Pulmonary diseases\*
Diabetes\* Hysteria

Diabetes\* Hysteria
Hemochromatosis\* Obsessive compulsive disorder (Koo

Lymphoma\* 2001)
Rheumatoid arthritis\* Uremia\*
Stress Depression\*
Heavy metal toxicity\* Henatic disease\*

Heavy metal toxicity\*

Hepatic disease\*

Carbon monoxide\*

Cirrhosis\* Small fiber polyneuropathy (Oaklander

Fluoride poisoning\* 2011) Illegal drugs

\*Conditions listed from Hinkle (2000) and Slaughter et al. (1998)

Small fiber polyneuropathy, (also called small fiber sensory neuropathy (SFSN)), is when peripheral sensory nerves under the skin are affected and present with unexplained pain, burning, tingling, pricking, numbness, coldness, creepy-crawly feelings, or electric shock-like sensations. Sufferers easily attribute the sensations to arthropod feeding activity and some spend years searching fruitlessly for an answer. This condition often goes undiagnosed. A woman who had simultaneous pricking sensations on both sides of her body had been told by her physician that she had "bed bugs." Once bed bugs were ruled out, the diagnosis was changed to "a form of dermatitis." It was later discovered she was pre-diabetic and appropriate medical care cured the problem.

# **Drug side effects**

Numerous over-the-counter and prescription medications can cause paresthesia (tingling, pricking, creeping sensations), urticaria (stinging, burning itch), erythema (redness of skin), hives (watery bumps), or pruritus (itching) (Hinkle 2000). The chances of having these side effects are increased with drug interactions (Doucet et al.1996, Aizenberg et al. 1991). Recreational drug use of methamphetamine, cocaine, amphetamine and/or alcohol may cause sensations of crawling or burrowing in the skin. The misuse of medications or tolerance reduction by continuous use of some drugs over long time periods can also cause DP (Hinkle 2000).

Most elderly persons need drugs for conditions such as glaucoma, pain, impotence, diabetes, arthritis, osteoporosis, heart disease, and hypertension etc. Drugs for these conditions can include beta blockers, monoamine oxidase inhibitors, estrogen, insulin, antidepressants, and pain medications with side effects of skin irritation. One in five Americans over the age of 65 take some form of prescription medication, and of those, 25% experience drug side effects or interactions caused by multiple drug use (Chrischilles et al. 1992, Doucet et al. 1996). Some commonly prescribed drugs (also drug types), which can cause skin irritation as a side effect, are listed in Table 2. Herbal remedies and nutritional supplements may also be problematic, especially if other prescribed or over the counter medications are taken with them.

Table 2. Some commonly prescribed brand name drugs which may cause skin irritation

Antibiotic	Antidepressant	Hypertension
Trimox	Prozac	Vasotec
Zithromax	Zoloft	Accupril
Biaxin	Paxil	Cardura
Augmentin	Elavil	Lotensin
Bactrim		Furosemide
Cipro		Procardia
Cfzil		Zestril
Keflex		Cardizem
Veetids		Tenormin

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Analgesic	Antihistamine	Sedative
Motrin	Claritin	Xanax
Advil	Ulcer	Ambien
Relafen	Pepcid	
Tylenol with Codeine	Zantac	
Bancap	Prilosec	
Lorcet		

List from Sandow (1998) and Hinkle (2000)

#### Commonly encountered insects-arachnids, which can cause dermatitis

Some insects and arachnids, which include mites, are of dermatological medical importance. These are listed below with brief explanations.

**Scabies mites,** *Sarcoptes scabei* (DeGeer). These mites burrow through the skin in specific locations on the body, e.g., between fingers, wrist skin folds, elbows, knees, penis, breast or shoulder blades. Scabies can be transmitted only by direct prolonged contact with an infested person such as a sex partner or immediate family member. Animals and pets do not spread human scabies; they have their own scabies-causing mites, which don't infest humans. Scabies in dogs is called mange. Hugs or handshakes do not usually spread scabies. Scabies is not common (CDC fact sheet -

<u>www.cdc.gov/NCIDOD/DPD/parasites/scabies/factsht\_scabies.htm</u>), and some itching complaints may be misdiagnosed as scabies. Samples should be taken and submitted to a medical or entomological diagnostic laboratory to confirm a scabies diagnosis.

**Straw itch mite**, *Pyemotes tritici* (La Grèze-Fossat & Montane). These hay or grain itch mites are insect predators often hunting grain, bean or pea pests. They are considered somewhat beneficial and have been used to treat fire ants. People who work with grain or hay can encounter this mite. In the Northeast, they are often found in deliveries of hay (also straw) for feeding horses or other livestock and become a nuisance to the animals and their owners by causing uncomfortable rashes. Horses often refuse to eat contaminated hay.

**Bird mites,** Northern fowl mite, *Ornithonyssus sylviarum* (Canestrini & Fanzago) and Tropical fowl mite, *Ornithonyssus bursa* (Berlese). These are pests of wild birds. In attempting to rid themselves of the mites, birds take dust baths using the abrasiveness of dry dust to help kill the mites. These mites stay with their hosts (host specific), but can become a problem to home or business owners during mid to late spring. When a bird nest on a building is abandoned, remaining mites start to wander in search of water. They may attempt to bite people resulting in a pricking sensation. These mites cannot live on people and are usually dead within two weeks after the birds leave.

**House dust mites**, American house dust mite, *Dermatophagoides farinae* Hughes and European house dust mite, *Dermatophagoides pteronyssinus* (Trouessart). These mites are very common and are scavengers of shed human skin. They do not bite people, but there is evidence house dust mites can cause contact dermatitis in some individuals through exposure to their feces and cast skins (Nadchatram 2005). They can cause allergic reactions to some

people if inhaled.

**Ectoparasites**, Fleas, mites, or ticks from dogs, cats, bats, rodents or other animals can be problematic to people. They have distinct biologies, and behaviors and are treatable.

**Lice.** Pediculosis is caused by *Pediculus humanus* Linnaeus (body louse) or *P. capitis* De Geer (head louse) or phthiriasis caused by *Pthirus pubis* (Linnaeus) (crab louse). These are transmitted via body to body contact or use of shared clothing. These may be common in situations where people congregate, such as schools, temporary housing, military barracks, or in shelters for the homeless.

**Garden thrips.** In periods of summer drought, thrips can prick the skin while seeking water. Sometimes they come into homes on plant material. They do not live on people.

#### Characterization of delusory parasitosis

Delusory parasitosis often is bewildering to the clinician, entomologist, and pest management professional, as well as the sufferer and their family or co-workers. Manifestations are as varied as the personality of each sufferer. Nevertheless, there are some common attributes. Sufferers usually complain of more than one of the several conditions listed in Table 3, and these "hallucinations" (Hinkle 2010), can be devastating. The cause is often the individual misinterpreting skin debris, secretions, color change, and/or sensations as arthropod activity.

# Table 3. Characterization of delusory parasitosis

Complaining of being bitten by insects

Obsessive cleaning

Eagerness to provide specimens

Some level of body mutilation

Self-treatment and medication

Involved biological descriptions of the "pest"

Rejection of psychological cause

Research including internet "surfing" to self-validate

Obesity and physical inactivity

Emotional trauma

Visits to numerous physicians

Social isolation

Expression of desperation

High numbers of specimens and/or repeated sampling



It is not uncommon for a diagnostic laboratory to be inundated with samples from a DP sufferer.

#### Manifestations of delusory parasitosis: some illustrative case histories

Sufferers sometimes experience problems for years. The longer they suffer, the harder it is to resolve. Those who have DP for less than a year have a better chance of resolution because DP has not become "a way of life". If it has existed for more than a year, it is more entrenched and clinicians report that sufferers are much harder to help. They often respond to negative test results by providing more samples, may refuse psychological help, and in some cases refuse to abandon their belief, so there is little hope of a "cure." (personal communication with Dr. Ted Lawlor, Department of Psychiatry, School of Medicine, University of Connecticut).

Following are some examples of DP incidents encountered in the insect inquiry diagnostic laboratory which may provide some useful insights into the problem. These cases are time consuming and often the entomologist needs to gain the trust of the sufferers, which can be difficult. Many have often experienced numerous previous encounters with other professionals, resulting in misinformation, misdiagnosis, and sometimes dismissive humiliation. Clients can be hostile and aggressively defensive until their trust is gained. Entomological support is limited to determining if there is actual arthropod involvement. Nevertheless, other factors may become apparent in the interview(s) and provide a basis for an investigation into other causes, or prompt referral to other professionals for assistance.

#### The work place

**Power of suggestion**. Situations of high stress or environments that are closed with no fresh air circulation can be difficult. In one call center, a female employee started complaining of being "bitten", which was soon followed by similar complaints from her adjacent coworkers. It continued to spread, until the entire department was involved, which included sixty employees. No evidence of arthropod involvement was found.

In the absence of this woman, complaints of apparent insect "biting" quickly stopped. The power of suggestion known as Bells' syndrome (Hinkle 2000) has high psychological contagiousness and in these kinds of settings where people are working in close proximity, it can become a problem.

*Static electricity*. A hospital laundry, which employed 40 people, is an environmental example. An inspection revealed unusually dry conditions caused by a dehumidifier that was too powerful for the space it was installed. A combination of low humidity and airborne fibers caused static electricity and once the dehumidifier was removed, the complaints stopped.

A call center had a dress code of nylon stockings for female employees. Many took off their shoes to be more comfortable while at their work stations. The call center was carpeted and humidity low. Complaints of lower leg insect biting became common. After investigation, no arthropods were found. It was later determined that the abrasion of the nylon stockings on the carpet caused static electricity, and thus the sensation of biting. The nylon dress code was changed, and the apparent biting sensations stopped.

#### Family and home

*Allergies.* One summer, a student civil engineer moved to Connecticut from the Midwest to work as a highway surveyor. He started to complain of being bitten by insects. It was found that he was allergic to the pollen of certain grass species only found in the Northeast. Post medication, the apparent insect biting sensations ceased.

In another case, a man had purchased a home by a major Connecticut river. He began to feel the sensation of insect biting. After exhaustive tests by an allergist, it was found that he was allergic to certain molds growing in and around the home.

**Delusory parasitosis projection caused by depression**. The projection of DP onto objects is rare. A woman became convinced her kitchen cabinets were infested with insects that would "fly out" and attack her. No other member of the family was affected. To appease her, her husband replaced the cabinets and the problem temporarily ceased, only to return. Interviews revealed that she had lost her mother two years before the onset of symptoms and she was subsequently diagnosed with depression (personal contact). Once treated, the apparent insect activity stopped.

*Stress*. The owner of a stressful business began complaining of insect bites. This also affected family members and employees, threatening the business. No causative insect activity was detected in the family home or business. A medical examination by a physician found no medical problems with the business owner. Following several interviews, he admitted he was suffering from stress and once he was treated, the apparent insect biting sensations stopped.

*Medical conditions*. A woman in her late 40's complained of being bitten by insects. There was no history of emotional trauma, but there was self-mutilation, compulsive cleaning, and self-medication. No causative insect activity was detected. A physician subsequently diagnosed hypothyroidism. Upon treatment, the apparent insect biting sensations stopped.

#### Response by medical professionals, entomologists, and pest management professionals

Physicians, especially dermatologists, entomologists, and pest management professionals (PMP) are specialists that most often encounter DP sufferers. The following suggestions may be helpful in interacting with and assisting sufferers.

- Be relaxed, calm, and maintain a professional distance, yet balance this with empathy. Slowly gain confidence and trust of the client giving plenty of time for interviews.
- Watch for red flags. Statements denying madness, willingness to show specimens, self-education using the internet, signs of self-mutilation through scratching and/or use of implements such as razors, excessive cleaning and/or self-medication behavior, use of pesticides, declarations of having a clean home/workplace, expressions of desperation, sleep deprivation, abandonment of sleeping area or sleeping in bizarre locations such as a car, elaborate descriptions of "pests' biology, that the "pests" show levels of intelligence, numerous visits to physicians, and some level of social isolation may all be indicators of DP.
- Determine whether there is arthropod activity. Involve clients with diagnosis. This develops a relationship based on trust and helps clients feel they are actively doing something about their problem rather than being passive victims. Teach clients how to use scotch tape on their skin for possible specimen collection; have clients collect vacuum samples using a coffee filter over the end of a vacuum hose to check for dust mites, other arthropods, and/or possibly bed bugs.
- Be careful what you say. Many DP sufferers have been dealing with the problem for a long time and will filter or latch onto unguarded words. For example, avoid using the words "book louse" but say "psocid". Though these insects are not lice, the name is enough to trigger anxiety.
- Avoid using inflammatory language such as "bite, biting, attacking", because this
  validates the client's belief system. Use terms such as "pinching sensation" or
  irritation which helps defuse anxiety.
- Ask about installation of new mattresses, rugs with artificial fibers, insulation, carbon monoxide, low humidity etc. Many environmental factors often cause DP.
- Physicians can inquire about medical history (allergies, medications, age, and medical conditions), trauma, and/or specific date problem started. In warm weather, there may be a genuine insect biting activity, which evolved into DP. Entomologists and PMP's are not physicians, so do not volunteer any medical diagnoses, but suggest clients visit a physician. Physicians should refer clients for psychiatric help, if appropriate.
- If arthropods have been eliminated from inquiry, encourage clients to seek a physician to pursue possible medical conditions and advise against self-prescribed treatments and excessive cleaning; especially use of pesticide-laced lotions and shampoos.
- Pest management professionals should avoid treating a home if there is <u>no evidence</u> of a pest infestation, even though there may be extreme pressure to do so by the client. Pesticides used in the home can exacerbate the problem (Hinkle 2000). Additionally, if the PMP chooses to treat using inert materials such as water,

- though symptoms may subside for a while (the placebo effect), they inevitably return. This may lock the PMP into a revolving cycle of treatments for a non-existent pest and in the long run, will do more harm than good (Hinkle 2010).
- If a client continues to have a problem over a long period without resolution and the client refuses medical or psychological help, it may be necessary to politely end the relationship.

#### Conclusion

Management of DP is extremely complex, difficult, and time consuming (Keh 1983). Care is needed in dealing with DP sufferers. If arthropods have been eliminated from an inquiry by an entomologist or PMP, they may suggest that the client seek assistance from medical professionals. The entomologist or PMP might suggest a physician collect suspect material and submit it; this encourages the client to seek a physician and puts the entomologist or PMP into the role of a diagnostic laboratory.

Delusory parasitosis is a poorly-documented under-reported problem, because it falls outside most scientific categories. Unfortunately, there is a tendency for DP sufferers to consult many specialists or be passed off without resolution of the problem. There is a need for a centralized multi-disciplinary diagnostic system, where professionals from medicine, the pest management industry, and trained entomologists network to help people with the condition. An inter-disciplinary approach will better prepare each professional group to deal with the syndrome.

# Instructions for client(s) to collect and submit samples for entomological diagnosis

- **<u>Do not submit</u>** human and/or animal body fluids, feces, or swabs of possible material of medical significance. These samples should be collected by a physician and submitted to a medical laboratory.
- Excessive sampling is not needed. A small number of samples is generally enough to identify most causative agents such as mites, pollens, plant or manmade materials.
- **Scotch tape sampling:** If a "pinching sensation" is felt on the skin, tap the site with a piece of scotch tape and adhere it to a small glass jar. Label the scotch tape with location, time, and date. Do not put tape onto paper or other supportive material. These contaminate the tape with fibers.
- **Vacuum sampling:** Cover open end of a vacuum cleaner hose with a coffee filter and hold firmly with one hand. Turn on vacuum cleaner and vacuum suspect surfaces until a dark disc of debris is seen across the hose opening. Turn off vacuum cleaner, place coffee filter into a sandwich zip-lock bag, and label.

# **Contact information for Dermatologic Support Groups**

National Psoriasis Foundation 6600 SW 92<sup>nd</sup> Ave., Suite 300 Portland, OR 97223-7195

Ph: 503-244-7404 or 800-723-9166

Web: www.psoriasis.org

National Alopecia Areata

Foundation 14 Mitchell Blvd., San Rafael, CA 94903 Ph: 415-473-3708

Web: www.alopeciaareata.com

National Vitiligo Foundation International Business Address National Vitiligo Foundation (International) 76 Garden Rd. Columbus, OH 43214

Ph: 614-261-8145

Web: www.vitiligofoundation.org

National Eczema Association 4460 Redwood Hwy., Ste. 16-D San Rafael, CA 94903-1953 Ph: 415-499-3474 or 800-818-7546 Web: www.nationaleczema.org

Obsessive-Compulsive Foundation 676 State Street New Haven, CT 06511

Ph: 203-401-2070

Web: www.ocfoundation.org

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