

**EURORDIS Membership Meeting Budapest
19 & 20 May 2017**



Workshop 2: Hope & Happiness are part of the treatment
Part 1: Natural, Alternative, Traditional, Complementary Therapies

Saturday 20 May 2017 - 9.40-10.00: Case Study

Case Study:
A Mushroom as a Dietary Supplement

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Contents

- I- A case study through the **5th Congress of Mycology 2016**
- II- Information accessible through the **Internet**
- III- Information from literature review (**PubMed**)
- IV- Conclusions

Oyster mushroom (*Pleurotus ostreatus*)



A case study through the **5th Congress of Myology 2016**



MYOLOGY 2016
5TH INTERNATIONAL CONGRESS OF MYOLOGY

AFMTELETHON
CURE THROUGH INNOVATION 

2016, March 14-18 LYON CONVENTION CENTRE
FRANCE

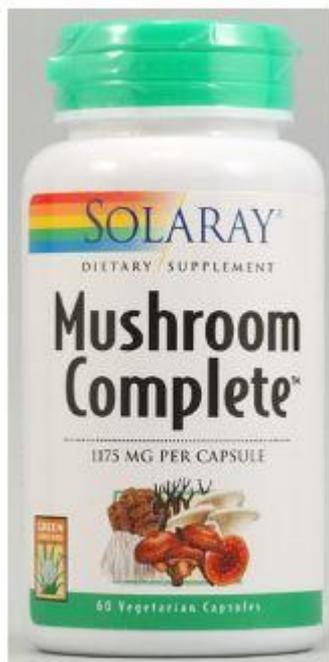
A case reported by Pr Andrew Mammen (Johns Hopkins Hospital, Baltimore, USA)

- ❑ A 40 y.o. male patient: muscle weakness, muscle biopsy, serum enzyme dosage confirmed an **immune necrotizing myopathy**.

- ❑ Symptoms were similar than those of a necrotizing myopathy encountered in some patients with side effects of « **statin** » **treatment for lowering cholesterol**.
 - joint pain
 - lower back or side pain
 - muscle aching, cramps, spasms, or stiffness
 - muscle pain, tenderness, or weakness

Necrotizing autoimmune myopathy

- ❑ Patient was diagnosed with necrotizing autoimmune myopathy, a **rare** form of inflammatory myopathy:
- ❑ **Diagnosis is based on:**
 - acute or subacute proximal muscle weakness
 - muscle biopsy: myocyte necrosis and regeneration without significant inflammation
 - electromyography (EMG)
 - creatine kinase (**CK**) levels : **X10 N** at the time of onset of muscle weakness.
 - **specific autoantibodies** (Anti-SRP, anti-HMGCoAR)
- ❑ Patient thought that symptoms were caused by a **mushroom dietary supplement** he took for a few months.



Directions

Use only as directed. Take two capsules daily with a meal glass of water.

Disclaimer

These statements have not been evaluated by the FDA. These products not intended to diagnose, treat, cure, or prevent any disease.

Supplement Facts

Serving Size: 2 Capsules

Servings per Container: 30

	Amount Per Serving	% Daily Value
Oyster Mushroom (<i>pleurotus ostreatus</i>) (fruiting body)	200 mg	*
Cordyceps (<i>cordyceps sinensis</i>) (extract)	150 mg	*
Turkey Tail (<i>coriolus versicolor</i>) (mushroom mycelium/brown rice biomass)	150 mg	*
Royal Agaricus (<i>agaricus blazei</i>) (mushroom mycelium/brown rice biomass and fruiting body)	150 mg	*
Lion's Mane (<i>hericium erinaceus</i>) (mushroom mycelium/brown rice biomass and fruiting body)	150 mg	*
Shiitake (<i>lentinula edodes</i>) (mushroom mycelium/brown rice biomass)	125 mg	*
Maitake (<i>grifolia frondosa</i>) (mushroom mycelium/brown rice biomass)	125 mg	*
Reishi (<i>ganoderma lucidum</i>) (mushroom mycelium/brown rice biomass)	125 mg	*
*Daily value not established.		

Other Ingredients: Vegetable cellulose capsule, cellulose, silica and magnesium stearate.

Warnings

Keep your licensed health care practitioner informed when using this product.

Amount of Lovastatin: Complement dietary vs drug

❑ Complement dietary Oyster Mushroom

up to **2.7% lovastatin** by **dry weight**

- **200mg** of **dehydrated** oyster mushroom/**serving size**
- 1 serving contains **5.4 mg lovastatin**
- Directions : 2 capsules/day

❑ Drug

- **Usual Adult Dose of Lovastatin (drug) for Hyperlipidemia**
- **Initial** dose: **20 mg** orally/day
- **Maintenance** dose: **10 to 80 mg** orally/day

Information accessible through the **Internet**



Oyster mushroom

(Pleurotus ostreatus)

- ❑ a popular **edible** mushroom that is commercially **cultivated worldwide**
- ❑ **Culinar** uses
 - frequently used in Japanese, Korean and Chinese cookery.
 - served on its own, in soups, stuffed, or in stir-fry recipes



Oyster Mushrooms for Healthy Cholesterol

By [Marcelina Hardy](#), Staff Writer on Thursday, April 5, 2012

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Whether cooked or taken as a supplement, these mushrooms are a smart choice for those with high cholesterol. Meet the top fungi.

If you're a mushroom fan, you will love oyster mushrooms. These tasty fungi not only have a delectable taste -- they are packed with vitamins and nutrients, making them a healthy addition to your diet.

Oyster mushrooms produce compounds called "**statins**" similar to those in **cholesterol-reducing drugs**

<http://www.mushroom-appreciation.com/oyster-mushroom-soup.html#sthash.kC3fE5cz.dpbs>

Dietary Supplements

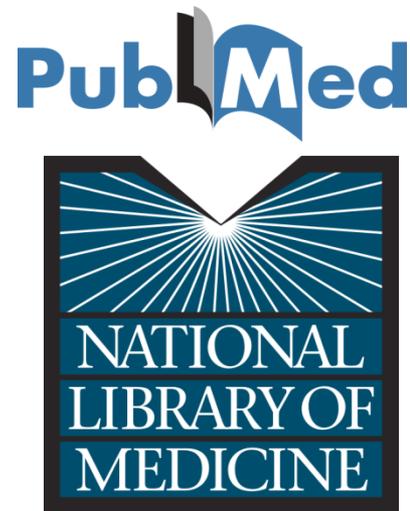
Oyster mushroom has **high nutritional value** as an important source of **protein, carbohydrates, vitamins, calcium, and iron.**



<http://www.healthbenefitstimes.com/oyster-mushroom/>

Oyster mushrooms Quick Facts	
Name:	Oyster mushrooms
Scientific Name:	<i>Pleurotus ostreatus</i>
Origin	It was firstly sophisticated in Germany during the World War I. It is grown economically in the world as a food.
Colors	White-gray or tan-dark brown (Cap)
Shapes	Convex and semicircular; Width: 1-12 inches, Thickness: 1/2-1 1/2 inches (Cap)
Flesh colors	White, firm, thick
Taste	Mild-strong
Calories	28 Kcal./cup
Major nutrients	Vitamin D (166.67%) Vitamin B3 (26.64%) Copper (23.33%) Vitamin B2 (23.08%) Vitamin B5 (22.26%)
Health benefits	Maintain blood sugar, Immunity system, Cardiovascular conditions, Skin problems, Brain health

Information from biomedical literature review (PubMed)



Oyster mushroom: Literature Search

- ❑ **Lovastatin** is present in high proportions in oyster mushroom
→ an important food supplement for patients suffering from hypercholesterolemia (Alarcón J, 2003).
- ❑ Its **extract** can **lower cholesterol** ([Khatun, 2007](#)).
- ❑ Potent **antinociceptive**, **antitumor**, **antioxidant**, and **immunological** activities ([Sarangi, 2006](#), [Vasudewa, 2008](#), [Jayakumar, 2009](#)).
- ❑ **High nutritional value** as an important source of **protein**, **carbohydrates**, **vitamins**, **calcium**, and **iron** ([Hilal, 2012](#)).

Conclusions

Sources of Information for Healthcare Providers & Expert Patients



✓ Internet



✓ Free search engine
on biomedical topics

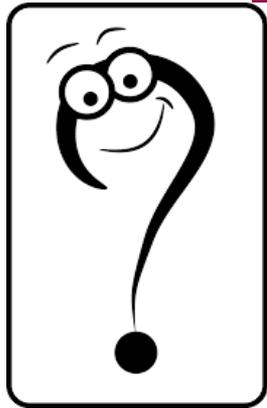


✓ Sharing experiences on social media
✓ Medical conferences



NATC Therapies in Rare Diseases

Consumers' demand for NATC, including dietary supplements has increased



It is urgent to:

- Collect** data
- Share** experience
- Work towards a **strategy** to generate **robust knowledge** on NATC
- etc....

