

**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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## Oyster mushroom (*Pleurotus ostreatus*)



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



**MYOLOGY 2016**  
5<sup>TH</sup> INTERNATIONAL CONGRESS OF MYOLOGY

**AFMTELETHON**  
CURE THROUGH INNOVATION 

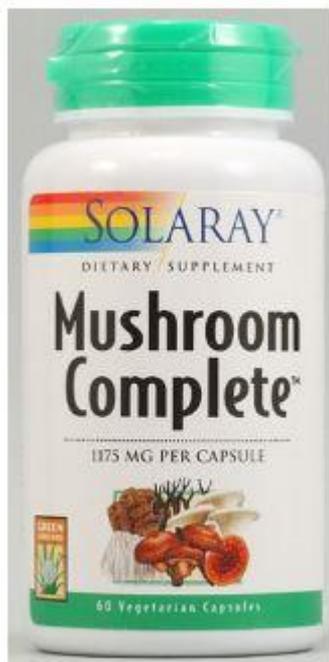
**2016, March 14-18** LYON CONVENTION CENTRE  
FRANCE

# 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

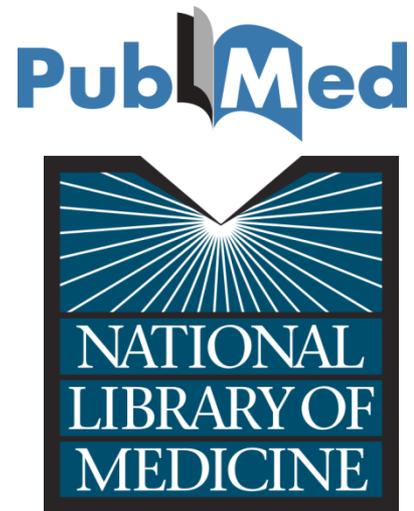
Oyster mushroom has **high nutritional value** as an important source of **protein, carbohydrates, vitamins, calcium, and iron.**



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

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

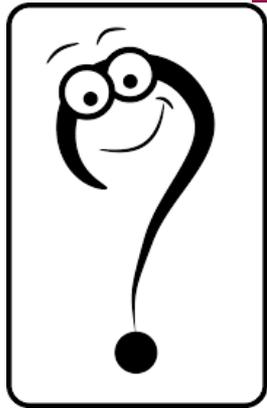


✓ Sharing experiences on social media  
✓ Medical conferences



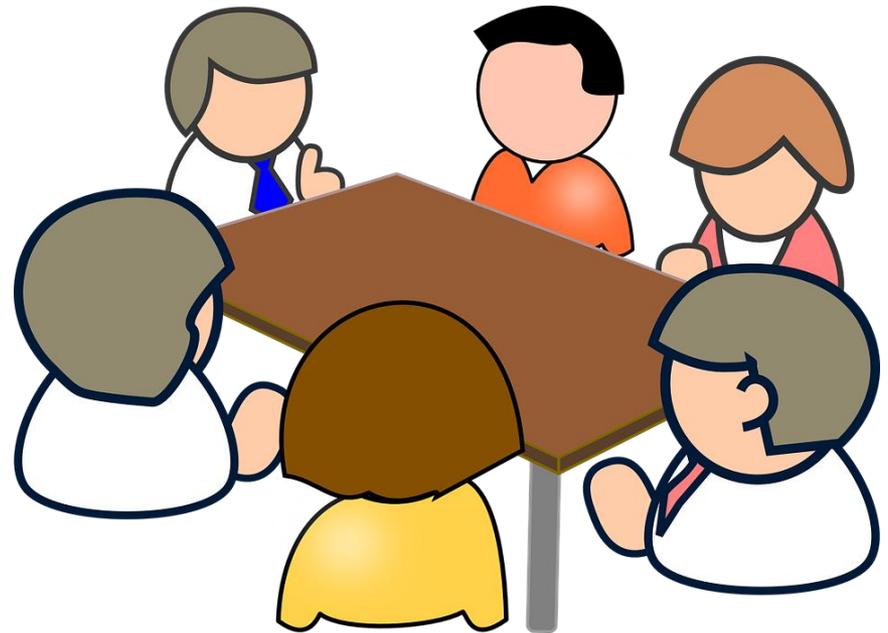
# NATC Therapies in Rare Diseases

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....





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