

WHAT IS DEGOS DISEASE OR MALIGNANT ATROPHIC PAPULOSIS?

It seems to be a disease of the blood vessels – a thrombotic vasculopathy. Cells in the linings of the walls of the medium and small veins and arteries under the skin swell when they become inflamed. This causes the blood flow to be restricted. Where this happens, spots (lesions) appear on the skin. They are small and red, slightly raised. As they develop, the centre becomes dry and white (atrophic). Sometimes the spots itch.

In some people, the disease stays at this stage and other symptoms do not develop. We know of one patient who was diagnosed in 1973 and is still well and working full-time. Be aware that information on some sites is *inaccurate*. You will read statistics and numbers which might scare you – but they are often based on projections and on published case reports. There are lots of Degos patients whose cases haven't been written up and who are alive and well.

There are also lots of confident assertions which just aren't true! For example: "This disease affects mainly young men" – not in our experience! Or "The lesions don't appear on the soles of the feet" – wrong again! Percentages and actual numbers can't be right, as no-one has compared living patients until now. Take it all with a pinch of salt and add *your* experience to our site and to the data being collected in Berlin.

Our collective knowledge will make the difference between assertive inaccuracies on medical sites and clear truth on this Degos Disease site.

Most of us are leading full and normal lives. Some patients have a few lesions on the skin; others have hundreds. We don't yet know if numbers are significant.

Sometimes the disease affects blood vessels in other parts of the body. Most commonly, the gut, the central nervous system or the eyes are involved.

Most case histories in the medical literature are of "worst case" scenarios.

From <http://www.degosdisease.com> (Information for patients)

INFORMATION

For physicians

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The **1st International Meeting on Malignant Atrophic Papulosis** is supported by the „Deutsches Register Morbus Adamantiades-Behçet e.V.“ (Charity German Registry of Adamantiades-Behçet 's disease)

1st International Meeting on Malignant Atrophic Papulosis

18th – 19th March 2005,
Berlin

**Program
of the
1st International Meeting
on
Malignant Atrophic Papulosis**

Friday, 18th March 2005

- 13.00** Welcome
- 13.05** Introduction - Focusing the subject
- 13.15** Medical presentation I - Malignant Atrophic Papulosis, a clinical synopsis
[Prof. Dr. med. Christos C. Zouboulis](#)
- 13.45** Medical presentation II - The skin biopsy: A major diagnostic tool
[Dr. med. Matthias Steinhoff](#)
- 14.00** Medical presentations III - Epidemiologic and first prognostic study on Malignant Atrophic Papulosis
[Dr. Athanasios Theodoridis](#)
- 14.30** Discussion
- 15.00** Coffee break
- 15.30** Specialist round table: Establishment of consensus diagnostic criteria for Malignant Atrophic Papulosis
- 19.30** Dinner

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Saturday, 19th March 2005

- 10.00** Patients examination

Congress Secretariat

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