

Internet Support Group on Mastocytosis

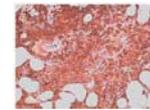
The Internet Support Group on Mastocytosis is a German support group for patients with Cutaneous Mastocytosis (CM) as well as Systemic Mastocytosis (SM). Additionally there is a new category of patients with a diagnosis of Mast Cell Activation Disorder (MCAD), the definition of which is still in progress. All we know at this time is that these patients suffer from the same symptoms as patients with CM and SM. We have a total of 100 patients in our support group. Most of them are from Germany, a few others come from Austria, the Czech Republic, Belgium and Denmark. Hence we are proud to consider ourselves a European support group.

Our Internet Support Group has an extensive web presentation comprising the WHO criteria of Cutaneous and Systemic Mastocytosis. These criteria describe the diagnosis standard as well as the classification of Mastocytosis. It also includes information about treatment options, anaesthesia advice, food recommendations, as well as a list of mast cell mediator-related symptoms. The group does not have its own journal, but because of good relations with the American support group, The Mastocytosis Society (TMS), the founder

of our group, Andrea König, writes a column, 'News in European Research', which is printed in the TMS newsletter. This newsletter is published quarterly. Our group is also in contact with the Mastocytosis Support Group of the United Kingdom. In our eyes it is important to build a patient network beyond frontiers.

The main activity of the Internet Support Group on Mastocytosis is to explain this rare group of diseases to patients. Cutaneous Mastocytosis is a more commonly known diagnosis, while Systemic Mastocytosis, as well as Mast Cell Activation Disorder, are rarely recognised by doctors. Hence it is a challenge and task to inform patients about their diseases. Furthermore doctors occasionally contact us with questions. In addition to providing information to both patients and doctors, it is our aim to listen to the patients and offer them support. This happens through the help of our internet discussion forum. You can find access to this forum on our website.

We also attend conferences run by European Competence Network on Mastocytosis in an effort to stay up-to-date with the latest research. It is also important to meet our experts, with whom we are in e-mail contact



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throughout the year, and in person from time to time. We feel this deepens these relationships and allows us to better express our daily needs and concerns.

Our goal in the coming years is to hold a support group meeting at which we can speak with each other personally. We also would like to invite speakers who will offer us further information about our disease. We are pleased that a few doctors have already expressed a desire to contribute and offer their expertise. Another goal is the publication of pamphlets that will provide additional information to patients and physicians about mastocytosis. ●

Andrea König
Founder

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Living with mastocytosis

In my case, it all started in 1995 with a few spots on the abdomen and I was very worried because I had never had such marks on my body before. I immediately went to the skin doctor where a sample was taken and its histology examined. It had been described as "Urticaria Pigmentosa" and I was just told that it could sometimes itch, and that it could be possible that even more spots would come. That was about it and nobody ever said anything about any kind of aftercare or another check-up. Thus, my spots became more and more numerous but if somebody asked me about them I would just say that it was nothing serious... it was only some kind of harmless pigmentosa. I never thought much about it, not even when my whole body was covered with pigments.

Over the last few years, I had many problems with my cardiovascular system, for example cardiac arrhythmia, fluctuating blood pressure and I very often struggled in my daily routine. I wasn't resilient anymore and had problems at work because I wasn't able to cope with the heavy workload and stress that comes with shift work. I had huge problems climbing stairs and after eating some particular foods, I nearly always had to go to the toilet immediately after the meal. I often had an upset stomach and acid reflux with strong pain but I always blamed it on my shift work and missing sleep. I sometimes had tachycardia until I suffered shock and even once I had to call the emergency doctor. The diagnosis was that I was overworked and should get my heart checked. My heart was checked back in 1999 and everything was in order.

In February 2006, I reached a point where I was again close to going into shock. I cooled down just as I did many

times before and went to my doctor the next day. He referred me to different doctors. When I came to a dermatologist, he couldn't believe what he saw: it was a bold mastocytosis he had rarely seen before! He talked about "Mast Cell Leukemia" and other things and referred me directly to a skin clinic. He couldn't believe that nobody had diagnosed the correct disease and he was shocked about that fact. Well, I was very glad that I had met this doctor and thanked him. If I hadn't visited him, I still wouldn't know what kind of disease I have!

Very quickly I got an appointment with the Dermatology Department at the Wiesbadener HSK (Wilhelm-Fresenius Klinik), and the doctors there were very involved with my case. Everybody worked hand-in-hand there and within the next 10 days of inpatient treatment GI tract biopsies were taken (with positive results and severe oesophagitis II°), a bone marrow biopsy (with severe positive results), as well as two ultrasounds of the abdomen (enlarged liver and increased spleen). A bone scintigraphy was also carried out (mast cell sediments in the upper arms, skull, thigh and both knees). They also determined the tryptase level in my blood as well as histamine metabolites in my urine. I also received an emergency rescue set that contains two tablets of "Tavegil", three tablets of "Decortin" 50 mg (now changed to liquid medication with "Fenistil" and "Celestamine") and an "Anapen 300".

Subsequently I was transferred to the Haematology/Oncology Department at HSK Wiesbaden. There they took 11 X-ray images from head to toe and a bone densitometry to exclude possible osteoporosis. The DEXA-bone densitometry was normal. They also took another bone marrow biopsy and sent it



to the University Hospital Mannheim, where they found the mutation D816V in exon 17 of the c-kit gene.

In 2007 an additional immune histochemical tryptase staining of my former bone marrow biopsy was done. The diagnosis was confirmed. It is Systemic Mastocytosis (ISM – Indolent Systemic Mastocytosis.)

My daily routine is very often tough. I get heavy pain in my bones and in the smallest situations where I get into stress; I react with problems in my cardiovascular system like tachycardia and blood pressure fluctuation. My skin also reacts very heavily. I also have big problems with heat! Food and drinks do not harm me in any way but I found that I would get very forgetful and sometimes I have to think a long time before finding the simplest words to explain something. Other affected people told me about having that symptom too.

I take up to 4mg of "Ketotifen", two tablets of "Pantozol 40" and one tablet of "Jodid 100" each day, plus some painkillers ("Paracetamol 500") if necessary. ●

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