

Alpha-1 panniculitis: bringing people together

November 2020

Dear All,

there are different reasons to develop a skin infection like PANNICULITIS, and Alpha-1-antitrypsin deficiency is one of them. The clinical signs can be very different from one Alpha to the other, but in general by treatment with antitrypsin, which is always an off-label use, infection regresses.

Unfortunately, as you know, antitrypsin as a drug is not available in all countries today.

Alphas in chronic disease with emphysema or liver problems learn how to arrange in different situations of daily life, adapt mainly by training, education and communication with other Alphas.

For Alphas with panniculitis the situation is a bit different: the presence of pain and infection are often dominating daily life, also they do not know other Alphas with the same disorder to share experiences.

The skin, as the largest organ of the human body, has various tasks, depending on where it is located. It separates our body from the outside, protects it from environmental influences such as heat, cold, humidity, wind, dust, dirt, dehydration, UV radiation, harmful substances, germs and much more. Often infection of panniculitis is located, not all over the body, so specific advices and personalized applications are to explore - they are essential for well-being.

There are only a few Alphas with panniculitis in Europe, and till now there is no structure to bring them together, to tell their stories and share their experiences.

As we know, in rare diseases social integration and psychological balance are main factors in quality of life. Alpha1 Deutschland and Alpha-1 PLUS, together with other Alpha-1 communities, would like to bring Alpha-1 panniculitis patients together, creating possibility to communicate in a group: Less for academic or research purposes, but to get out of loneliness, to share experiences, to find new connections, to feel somewhere being part of the group.

BUT WE HAVE TO FIND THEM!

And therefore like to ask for your support:

***If you know people with PANNICULITIS, pass on our letter to them
and if you ask them to contact us, privacy will be respected.***

Thank you very much for your help!



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