

IBD Patient Meeting – Feedback from attendees at meeting held during ASSA SAGES Congress in Port Elizabeth on Saturday 5 August 2017 at the Boardwalk Convention Centre

The feedback from the patients for the IBD Patient Meeting was very positive. The patients found it very informative, well organised and professionally presented. They thought it was worthwhile and valuable - many found the information very beneficial to a better understanding of their condition. They had many “Why” questions answered and some “Aha” moments.

A patient mentioned that she was very excited to have an event like this in Port Elizabeth and to see progress being made here. She has been following advice from a UK website as she stated that most South African websites have “died”.

One patient stated the following: “I found it extremely informative and presented with great empathy, with the plight of the patients truly at heart.” This was a common point of feedback from many of the patients.

Another patient stated: “The meeting was very professional and informative and the people I am in touch with on our FB patient support group have already benefitted from information provided. It has also facilitated a get together coffee morning, where we can all chat and share peer to peer information and advice.”

The husband of one of the patients suggested an annual event where each person can share their improvement in their condition. He also mentioned it was good to find out that his wife is not alone in her condition, and to hear of the on-going research.

In general, patients seemed to learn a lot about their condition, to be reassured that they are not alone and to be encouraged to network and connect with relevant people through social media and websites. Those who attended as companions to patients, or to learn more about the condition for various reasons, seemed to enjoy the interaction between speakers and patients and found the information received to be valuable in assisting those around them with the condition.

Many of the patients complimented the excellent speakers. Speakers that stood out were Karin Davidson, David Epstein and Emile Coetzee, and especially Prof Ghosh.

The only negative comment was from one patient who said the speakers were a bit too complicated to understand.