

## Wolfram Nolte Testimonial<sup>1</sup>

**Wolfram Nolte, 70 years old, Neuss, Germany, patient advocate with colorectal cancer and stenosis**

I am a 70 year-old man, married and with one son. Prior to my retirement in 2008 I was working as an international sales manager. I studied law and later I also did a web-based vocational education programme for business people.



In 2004 I was diagnosed with Attenuated Familial Polyposis (aFAP) of my proximal colon out of clinical sight, which was however not supported by human genetic findings. At the beginning of 2009 I was diagnosed with a 4th stage metastatic colon cancer which took its origin from a hyperplastic adenoma in my caecum and which had grown within 9 months after my previous colonoscopy.

Consequently my entire colon was removed and I am now living with an ileorectal anastomosis. The subsequent chemotherapy was successful at fighting back my hepatic metastasis and kept me alive up until now.

Another of my health problems originates from my younger days when, at the age of 30, I was operated from a lumbar subdural tumor. The operation prevented me from sitting in a wheel chair however it did not keep me from having problems with my back and my legs. For the last 20 years I have suffered from spinal stenosis which limits my walking range.

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Since 2004 I have been actively engaged in patient support groups. This has helped me considerably to cope with my cancer diagnosis and my life afterwards. I am working now in leading positions in different patient advocacy organisations: European Colon, the Familienhilfe Darmkrebs (Family support with hereditary CRC), Lynch Syndrome International (LSI) and the Patient Advisory Board of the Centre for Rare Diseases at the University Clinics of Bonn.

In June this year I had a surgical operation for the replacement of my right hip link by an endo prosthesis. I had been painfully waiting for the operation for the last two years, until my oncologist saw a chance to pause my chemotherapy since such an operation is by no means advisable while running chemo therapy. This was my second operation of this kind since my left hip link was replaced already in 2007.

I am here today because my care was well coordinated, although it was not easy to wait for the hip replacement I needed. The interactions between the doctors were good and I was involved at all points and fully informed. Unfortunately, I know of different experiences than mine, of cases in which patients have experienced much more difficulties.