

Bert Spangemacher (foto's) en Jan Geissler: 'Faces of Courage and Hope' 16 inspiring journeys of people living with chronic myeloid leukaemia. CML Advocates Network 2014.(Kanker/ Leukemie/ Informatief/ CML/ PO)

Soort boek/ Ziekte/ stijl:

"Maybe twice a week I realise that I am on the lucky side of life. I'm still very grateful about that. For many years I found it very difficult to accept that I lost my job due to my diagnosis. But now I do voluntary work instead, which is very satisfying."

Monique from the Netherlands

Engelstalig boek met 16 portretten van mensen uit 15 verschillende landen die leven met CML. Boek van 140 pagina's.

<http://www.hematon.nl/nieuwsberichten/faces+of+courage+and+hope>

'Portretten en verhalen van mannen en vrouwen met CML uit 15 verschillende landen, waaronder Monique uit Nederland. Mensen van verschillende leeftijd en met diverse achtergronden vertellen hun verhaal. Hoe de diagnose hen overviel, waar ze hulp zochten, hoe de aandoening hun leven heeft veranderd.

Over de schrijvers:

Jan Geissler: zie <http://www.patvocates.net/about-patvocates/jan-geissler/>

Bert Spangemacher (foto's): zie <http://spangemacher.com/>

Extra:

Verkrijgbaar bij Amazon en bij Hematon tegen kostprijs (€ 15,00 inclusief verzendkosten), zolang de voorraad strekt. Stuur een e-mail aan voorzitter.leukemie@hematon.nl

CML Advocates Network geeft ter gelegenheid van Wereld CML-dag (22 september) een boek uit met 16 inspirerende verhalen van mensen met chronische myeloïde leukemie. Portretten en verhalen van mannen en vrouwen met CML uit 15 verschillende landen, waaronder Monique uit Nederland. Mensen van verschillende leeftijd en met diverse achtergronden vertellen hun verhaal. Hoe de diagnose hen overviel, waar ze hulp zochten, hoe de aandoening hun leven heeft veranderd.

https://www.youtube.com/watch?v=8ne_HjZrW_Q

MINA from France

For Mina, the ladybird is a symbol of hope because it is linked in her mind with the joy of regaining her health after six years of being bedridden. A lawyer by training, the 44-year-old now puts her professional skills to good use as a patient advocate. Mina is the founder of LMC France, the country's first nationwide CML patient organisation. She lives in Marseilles with her husband Stéphane, who is vice-president of LMC France, and their two teenage children.

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overprotective and talk about me as if I'm fragile. My oldest daughter has picked up on that.

WHO HAS BEEN A SOURCE OF SUPPORT TO YOU SINCE YOU GOT CML?

I have a very good relationship with my doctor. But my best source of emotional support, the person I can confide in, is my husband. He's shared all the moments, good and bad, with me. If I feel worried, he is the only person I can really talk to. But now that I've been in remission for several years, we don't talk about CML much.

Talking of support, I feel that patient organisations are very important. When I was first diagnosed, it would have really helped me to share experiences with other CML patients. Now there's much more help available. It's vital that such organisations continue with their work of giving hope, sharing information and allowing people to talk about their experiences.

WHAT DO YOU DO FOR FUN?

Most of my spare time is spent with my two small daughters, going on trips to the beach or the park. Where I live, near Dijon, we're just a 20-minute drive from beautiful beaches. Of course Miguel and I also spend time together as a couple when we can – we leave the

kids with their grandparents and go to a movie! Or maybe we will cook or meal for friends. My speciality is pasta and Miguel likes to make sushi.

DO YOU HOPE FOR A CURE FOR CML?

I feel I'm already cured because I stopped treatment before my second pregnancy four years ago. I lead a normal life. Sometimes I think that one day the illness may return, but even if a cure was invented, that possibility would still be there in my mind. So a cure would make no difference to how I feel. Right now, I feel perfectly healthy.

WHAT ADVICE WOULD YOU GIVE SOMEONE WHO'S JUST BEEN DIAGNOSED WITH CML?

Nowadays, a CML diagnosis is a much more positive thing than it might have been 10 or 12 years ago, before the recent advances in treatment. But the word "leukaemia" always frightens people. I would advise that person to become as well-informed as possible, talk to their doctor, find out about available treatments and above all realise that a CML diagnosis today is a diagnosis full of hope. I would offer that person all the hope in the world.

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Michelly spends much of her spare time going on outings with her husband and her daughter.

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Her favourite beach is just a 20-minute drive from home.

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Michelly says her husband Miguel is her best source of support. "He's shared all the moments, good and bad, with me."