



Patient Advocates; how do we work (together)?

A Patient Advocate is an inspired and committed individual with a unique gift to accelerate better cancer prevention, diagnostics, treatment and after care. We meet up to support each other and create bigger impact.

The essence of Inspire2Live (I2L) is bringing together patients, researchers and clinicians to accomplish our mission. I2L is a platform of patient advocates (PA's): highly educated and committed patients, cancer survivors and loved ones from diseased. PA's are well informed and eloquent. They are aware that they're not always invited at the discussions where decisions are made. However; we'll always emphasize the benefit for the patient and our mission.

When we really want to change the research done for cancer patients and the treatments that are being developed for them, we have to set up the cooperation with researchers and clinicians. Our vision is in more detail outlined in our vision document: <http://inspire2live.org/wp-content/uploads/I2L-PA-Vision-Document1.pdf>

I2L is about networking. Our PA's work individually or in small groups that have defined their own targets in the fight against cancer. Four times a year we meet and discuss the themes that we share and investigate whether working together in bigger groups accomplishes what we're aiming for, but it is essential that each PA is able to determine her own goal and means to reach that goal. Why? PA's have an acute awareness of specific parts of the cancer health system that could perform better. This awareness is the source of our motivation to address them. Fuelling this motivation is key to I2L. To that extent we use each other's talents and potential and contribute to it to the best of our possibilities. We align with each other's purpose and activities as much as we can. Problems that arise and differences of opinions are the fuel for the development of our organization. Next to this have our PA's a high visible profile and are present at as many meetings and congresses as possible and tell the audience about our mission and activities. The organization, if possible, facilitates this with the available resources from office management, program management, finance and communications. We work as a relatively small group of around 40 PA's and are not a community of many patients, however lot's of patients can and will contact us for help, activism and representation but will not be part of I2L.

The PA's meet each other in different ways. This can be done in meetings face to face, conference calls and so on. The meetings are between two or three PA's or larger teams. When we meet as a group, we invite a keynote speaker to increase our overall knowledge and spark discussions on specific themes. After that we take some time to inform each other and to ask for help. Meetings take place on the basis of a strict and clear structure, with room for initiative and influence of all employees.

Meeting time is precious time, in the sense that we can make something precious during our meetings. A meeting is a unique opportunity to leverage and pick the "fruit of dialogue." Characteristic of this fruit is that it leads to action. Each PA comes loaded with information, knowledge and questions about her activities to the meetings. All that really matters is to be discussed. Besides information given there is the opportunity to ask for help. And off course; give help.

The essence of our meetings is 'inspire each other', 'inform each other', 'get help from each other' and 'perform'.

never ever quit!