



Das Lebenshaus

**Kai Pilgermann**

**Chairman**

**Das Lebenshaus e.V.**

**(The House of Life Assoc.)**

**Patient Advocacy Organization**

**GIST \* Sarcomas \* Kidney Cancer**

*„Independent,  
well-informed and active!“*

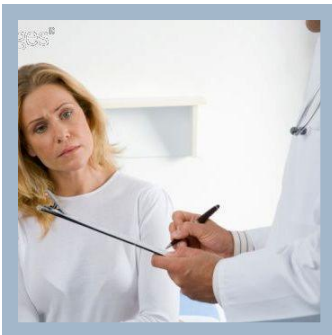




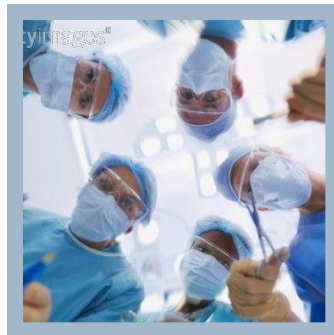
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## Das Lebenshaus – Today (Philosophy)

Patients, caregiver, non-patients, medical experts, representatives of pharmas and other stakeholders are working close and professionally together to achieve the best for the patients and their families:



Information &  
Support



Treatment:  
\* Access  
\* Quality



Future look:  
\* Research...



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## Objectives/Tasks



Survival,  
a "normal"  
life with the disease

Sarcomas	<b>Hope</b>	06/2009
	<b>Research</b> (support)	
	<b>Treatment</b> (access, quality)	
Kidney Cancer	<b>Support/Advocacy</b>	02/2008
	<b>Information</b>	
	<b>Basis: „Independent, well-informed and active!“</b>	
GIST		06/2003



## Success factors

Knowledge  
about non-profits

**Vital leader/s –  
active people –  
patients, carer, non-patients  
(...with different skills...)**

Clear  
philosophy,  
statutes, rules, etc.

Medical knowledge

Professional coop.  
with experts, pharma,  
other stakeholders  
(peer to peer)

Networking  
local \* national \*  
international

Professional  
(marketing-)  
communication

Healthy  
financial basis

Self confidence  
and independence



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Challenges for PAGs (Patient Advocacy Groups)

**Our main challenge in cancer?**

**To keep patients alive...**



## Challenges for PAGs (Patient Advocacy Groups)

- Vital leader/s - active people (...not only “consumers”...)
- If only patient led: Next potential leaders...???
- Knowledge/education: How to start, manage, strengthen a PAG? (It’s hard to start!)
- Healthy financial basis (topic of professional fundraising)
- The big difference between “rare diseases and common diseases”
- To be accepted by other stakeholders (peer to peer)
- To be involved by pharma: f. e. information, clinical trials
- Poison: Public discussion “financing through pharma”
- Old fashioned (traditional) imagination on PAGs
- Per country: Political history, situation of the healthcare-system
- European focus: to see beyond one’s own nose



*The European Network of Sarcoma Patient Advocacy Groups.*

## **A Better Future For Patients With A Rare Cancer!**

- Increasing the awareness of sarcoma
- Providing information and support
- Improving treatment and care
- Supporting research
- Building capacity

**Contact:**

Fon: 0049-6032-9492-881

Fax: 0049-6032-9492-885

[spaen@lebenshauspost.org](mailto:spaen@lebenshauspost.org)

[www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)





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## Contact

Das Lebenshaus e.V.

Patient Advocacy Organization Sarcomas \* GIST \* Kidney Cancer

Chairman: Kai Pilgermann

CEO: Markus Wartenberg

Usa-Strasse 1, D-61231 Bad Nauheim/Germany

Fon.: +49-6032-9492-438

Fax: +49-6032-9492-885

[pilgermann@lebenshauspost.org](mailto:pilgermann@lebenshauspost.org)

[wartenberg@lebenshauspost.org](mailto:wartenberg@lebenshauspost.org)

[www.daslebenshaus.org](http://www.daslebenshaus.org)