



Leukämie
online.de
Die Online-Gemeinschaft zum Thema Leukämie

European CME Forum 2010

Patient information – and how patient advocacy can strengthen education and best practice

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Most frequented leukemia patient community in the German speaking web



Umbrella for 315 cancer patient organisations in



Platform for 51 leukemia groups in 43 countries



Initiated by leading hematologists; patient in scientific advisory committee & staff

Time is often of essence in the rollercoaster patient journey

- **After diagnosis, time is of essence in cancer** (and many other life-threatening diseases)
- **Taking tough decisions quickly** is difficult for the patient, family and caregiver



Having a life threatening condition like cancer, access to information is crucial

Cancer patients need to take informed decisions:

1. Understand the disease
2. Find the right doctor
3. Find **other patients**
4. Understand & consider **trial** participation
5. Decide on **therapy**
6. Know about **interactions, adherence, complementary medicine**



Improved information can improve outcome.

Patient advocacy groups' role has evolved dramatically



Support & inform patients

- Reduce fear
- Find the right doctor
- Provide patient information



Advocate in Health Policy

- for better access to treatment
- for better/patient-centric regulation



Research Allies

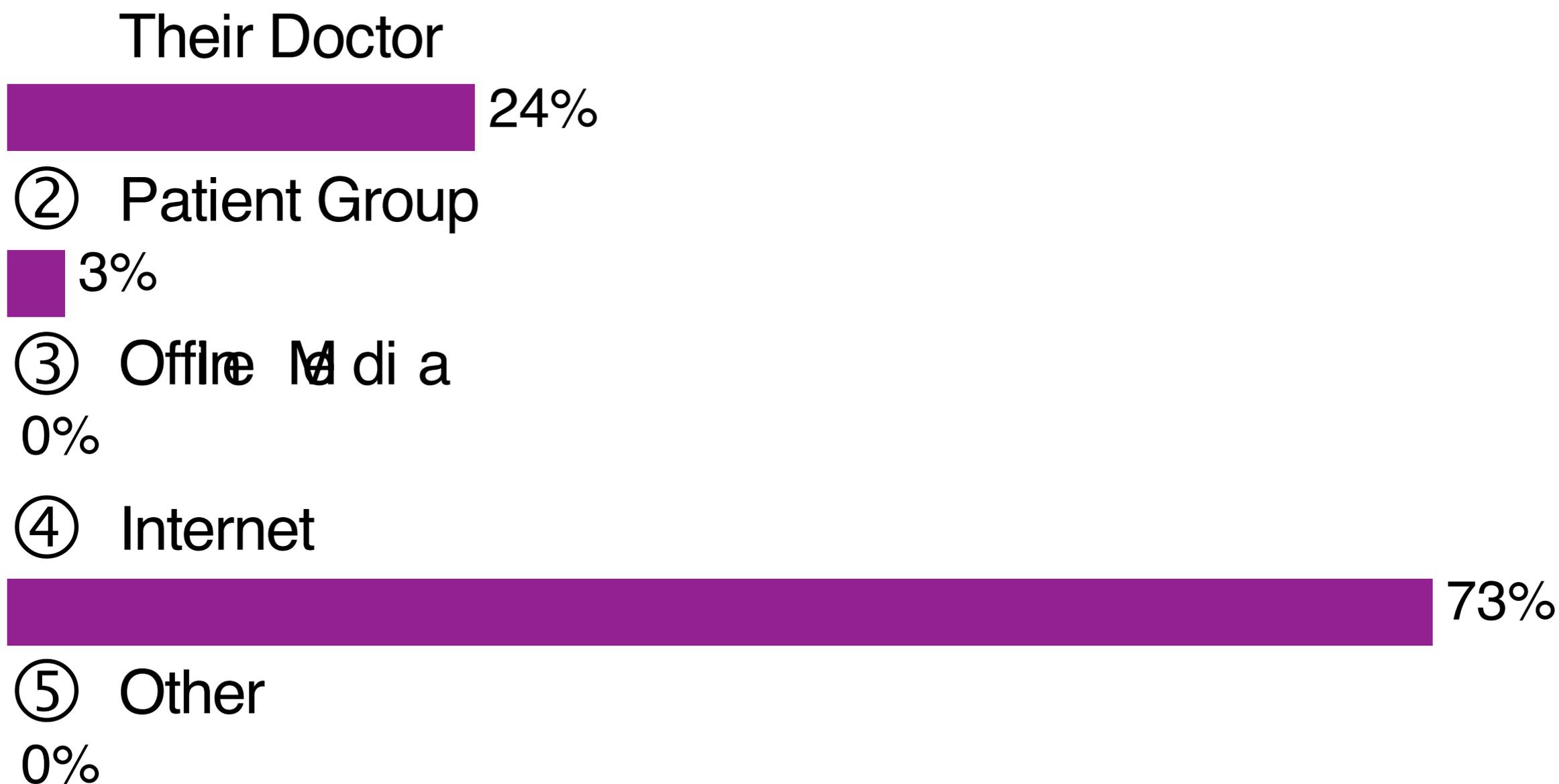
- Collaborate with clinicians & industry

"Nothing about us without us!"

Keypad question



What is the primary information source of cancer patients today?



Are we trying to threaten or substitute the doctor-patient dialogue? No!



- **The doctor remains the primary partner** of a patient in healthcare.
- However: Healthcare systems do not incentivize detailed consultation: ~12 minutes from door to door.
- Patient groups support the patient to **understand what he heard**, and to **prioritize questions** to the doctor

The Internet is transforming educational needs



- Health information seekers:
 - ~55% of EU adults go to their doctors
 - **~45% EU adults use the web to obtain health information.**
 - **~33% of patients talk to their doctors about what they found online**
- **Google won't go away, transforming the needs of patient and doctor education (on new media).**
- Sources: iCrossing, Manhattan research (2008)



More transformational drivers on education



- Need for **multidisciplinarity and holistic care**
 - **Health Technology Assessment**
and "better value for money"
 - Need for **Patient centricity**
- **Doctor education needs to reflect**
that the walls of "walled gardens"
have already come down

Are patients trying to become better scientists? No!



- Common goal:
To get better answers to patients more quickly.
- **Patients have unique expertise** that complements that of medical professionals, e.g.
 - **What it means to live with the disease**
 - **Explain the value** of participation in trials, and outline inhibitors
 - **Review of "informed consent"** documents
 - **Disseminate trial results** to be used in daily practice
 - **Insight** on interactions, adherence, CAM use, Quality of Life (also for HTA!)

Patient voice at scientific conferences has become a reality

- **Patient voice heard at scientific conferences in the last 2 years**

- **ESO Nurses Group**
- **ASH** (Satellite symposium, patient survey)
- **ECCO** (full advocacy track)
- **German Cancer Society AIO** (informed consent)
- **EHA** (patient advocacy track, satellite symposium)
- **DIA** (ethics, information to patients policy)
- **EORTC** (clinical trial insurances)
- **German Cancer Research Center** (target therapies, gene profiling and ethics)
- **ESMO** (patient seminar)



EHA Annual Conf2010, Barcelona
Satellite Symposium "Evolving
concepts in management of CML"

Patient voice at scientific conferences is appreciated as valuable and complementary

- **Greatly valued by health professionals**

- *"I never realized non-compliance is such an issue in cancer therapies"*
- *"I had a very different perception what it means to live with the disease."*
- *"I was unaware complementary medicine is so widely used by my patients, despite the risks."*



EHA Annual Conf2010, Barcelona
Satellite Symposium "Evolving
concepts in management of CML"

Keypad question

Do health professionals be proficient in English language to be up to date on state of the art cancer treatment?

Yes



② No



Patient communities may be educational platforms for health professionals, too

- **Leukaemie-online.de: Most frequented leukemia patient community in the German web**
- Grassroots initiative started in 2002, run by patients
- **Providing news from research and scientific conferences into German (lay) language – and a forum**
- **Regularly (anonymously) followed also by doctors and nurses**

The screenshot shows the homepage of the German leukemia patient community website, Leukämie-online.de. The browser window title is "Leukämie-Online :: Die Community zum Thema Leukämie - Windows I". The address bar shows "http://www.leukaemie-online.de/". The website header includes the logo "Leukämie online.de" and the tagline "Die Online-Gemeinschaft zum Thema Leukämie". A navigation bar contains links for "Homepage" and "Suche".

The main content area is divided into several sections:

- Neues & Foren**: A list of links including "Nachrichtenthemen", "Archiv älterer Artikel", "E-Mail-Newsletter", "SMS-Erinnerung", and "Diskussionsforen".
- Über Leukämie**: A list of links including "Über Leukämie", "Neu diagnostiziert?", "Häufige Fragen (FAQ)", "Leukämie-Lexikon", "Bücher", "Artikel-Download", "Links im Internet", "Spenden", and "Über uns/Impressum".
- Aktuelle Termine**: A section with the text "Für die kommenden Wochen ist kein Veranstaltungstermin".
- Willkommen bei Leukämie**: A welcome message stating that Leukämie-Online e.V. is an independent German-speaking communication platform for leukemia, run voluntarily and for the benefit of patients. It mentions that the platform is very interesting for patients to ask questions and answer them, and to publish event dates.
- Dasatinib erhält Erstlinienzulassung für CM**: A news article dated Friday, October 29, 2010, at 22:32. It reports that the American FDA has granted first-line approval for Dasatinib (brand name Sprycel) for the treatment of new CML. It notes that in the USA, it is now used alongside Imatinib. A small image of a blue pill is visible next to the text.
- Deutschland Europas Spitzenreiter bei Kno**: A news article dated Friday, October 29, 2010, at 22:32. It states that Germany is the European leader in bone marrow transplantation. It mentions that a total of four million potential donors are available. In an international comparison, Germany is behind the USA, which has about six million registered donors. A small image of a blue pill is visible next to the text.

Patient groups can support and complement doctor and nurse education

- **Involvement of patients in doctor and nurse education provides complementary insights, e.g. on**
 - providing **patient centric care**,
 - **identifying unmet needs** in research,
 - improving **informed consent** and trial recruitment
 - recording and improving **quality of life**,
 - making **doctor-patient communication** more effective,
 - spreading **best practice of care**.
- **Patient involvement will strengthen, not weaken education of professionals!**

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