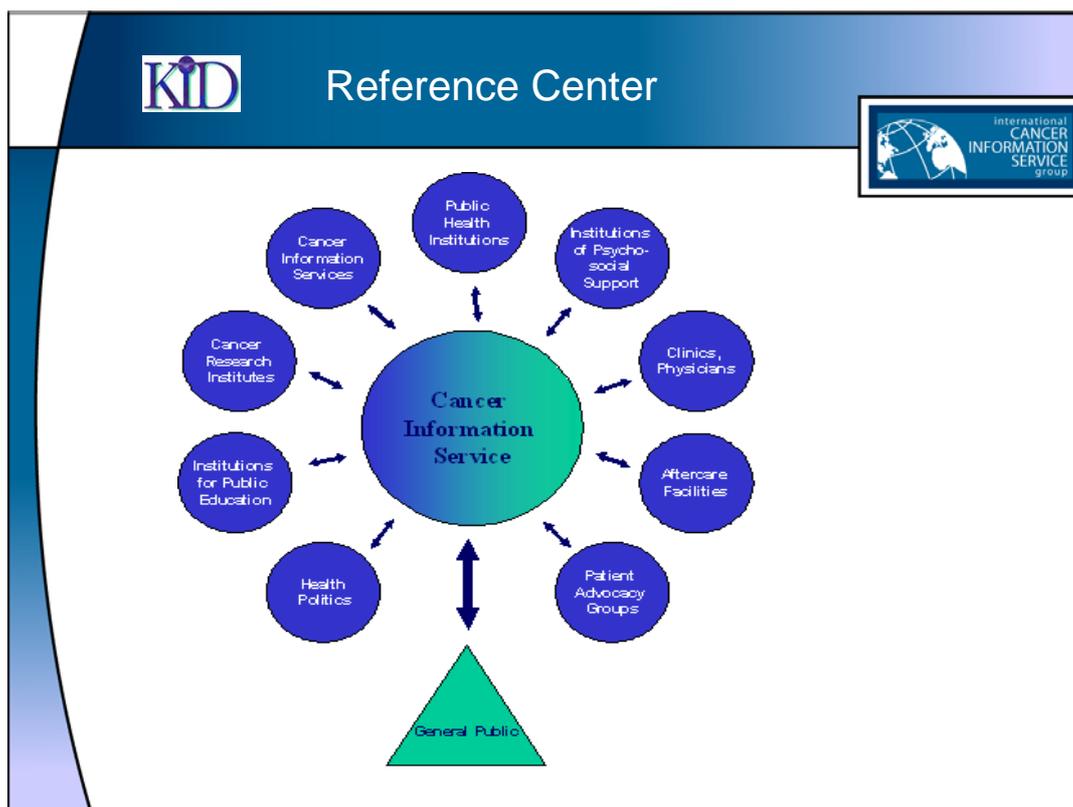


4<sup>th</sup> UICC World Conference for Cancer Organizations, Dublin, November 2004

## New Ways of Communicating Cancer Information: A Modular Approach

Monika Preszly, Cancer Information Service, German Cancer Research Center

A CIS in any country has the potential not only to disseminate high quality cancer information but to serve as an indispensable reference center for cancer information and communication.



By linking all available resources a CIS can support cancer control and help to improve the situation of cancer patients and their families.

A CIS is a provider and at the same time a recipient of manifold information about callers' concerns, their beliefs and ideas, and their actions. And in turn, the service can pass this information on to organizations involved in cancer control and education. This gives us the opportunity to open up new channels of communication and not only to reach more people but to provide specific target groups with information tailored to them, and to answer changing needs quickly.

## KID: Facts and Figures



- **Start:** 1986 at the German Cancer Research Center Heidelberg
- **Main Sponsor:** Federal Ministry of Health
- **Information via:** Telephone, E-Mail, Internet, Publications  
*in Planning: Face-to-Face Counselling*
- **Answered Inquiries** (1986-2003): 220,000
- **Type of Caller:** Patients (44 %), Relatives (41 %)
- **Motives for the Call:** Personalized Assessment, Reassurance,  
Orientation and Guidance in the Health Care System
- **Main Subject of Inquiry:** Treatment (64 %),  
Need of Orientation and Guidance (15 %)
- **[www.krebsinformation.de](http://www.krebsinformation.de):** 9,2 Mio. Requests  
(outside Firewall, without homepage)
- **Brochures:** 30,000 sent by Request

When the German Cancer Information Service started in 1986 as one of the first cancer information services in Europe, we had a very small budget, not much staff, and we did not know if funding could be obtained for more than one year. But we were determined to make a difference.

Right after the start it became clear that the demand for cancer information in Germany was much higher than our limited staff capacity. Therefore, from the beginning on, we have been looking for new ways to improve the access to high quality cancer information for patients and their families, to information that is tailored to their specific needs. This is not just a matter of large amounts of money to start with (though this definitely helps) but of an awareness where the areas of greatest needs are in a specific country – and the commitment to highest quality standards.

To keep and improve these standards, and to explore new trends that might prove helpful for cancer patients we have set basic priorities for our work.

Among these are:

## KID Focus on



- Cancer Information based on Available Scientific Data
- Quality Assurance
- Custom-Made Data Base
- Evaluations
- Collaborations
- Involvement in New Developments

- KID disseminates **cancer information based on available scientific data**, researches new topics and questions and translates this information into language that can be easily understood by our users.
- From the beginning, highest priority has been given to **quality assurance**. A highly qualified staff is the prerequisite for successful work and development of a CIS.
- Also right from the start, KID has been using a **custom-made data base**: all information and data that are researched and obtained by the KID staff are fed into it and can be accessed for answering calls right at the phone. (This data base which by now is web-based, includes up-to-date information on all aspects of cancer as well as as extensive information on existing facilities for treatment, rehabilitation and counselling. We do regular surveys to keep it up-to-date.)
- Each call is documented on a **call record form**, encoded and evaluated. This provides an extensive pool of data which gives a good insight into the concerns and problems of cancer patients and their families: what do they want to know, where are the areas of greatest need, and where are deficits in the provision of information and care, and of course helps us to improve our service.

There have been tremendous changes in the role and rights of patients and their information seeking behaviour over the past 18 years. This development has expanded the range of KID's activities and goals.

### Enlarging the scope of KID information by Meeting Special Needs

Offering special hotlines and other modules has many advantages, for those who offer them, and for the users:

It is a good way to meet specific needs on various levels: national, regional, provide special target groups with information tailored to them, track specific deficits. It is easier to raise funds for a special module than for a cancer information service as a whole.

Once you define an area where the need for information and support is great, where potential sponsors are available (who will not try to influence the information you are giving), and where public and political interest is existent, there are good chances for the implementation of such a hotline.

Here is an overview of the hotlines we have added, and how many more people we could reach with these modules:

KID Statistics 2003		
	Answered Inquiries	18,200
	KID Telephone Service	12,535
	Email Service	2,532
	Breast Cancer Hotline	1,783
	Fatigue Hotline	450
	Cancer Pain Info. Service	900
	KID Internet Requests	2.8 Million
	Brochures sent on Request	30,000

With these special services were also able to collect valuable data about needs, gaps and trends concerning specific target groups, and give feedback to decision makers in politics, health policy, treatment and care.

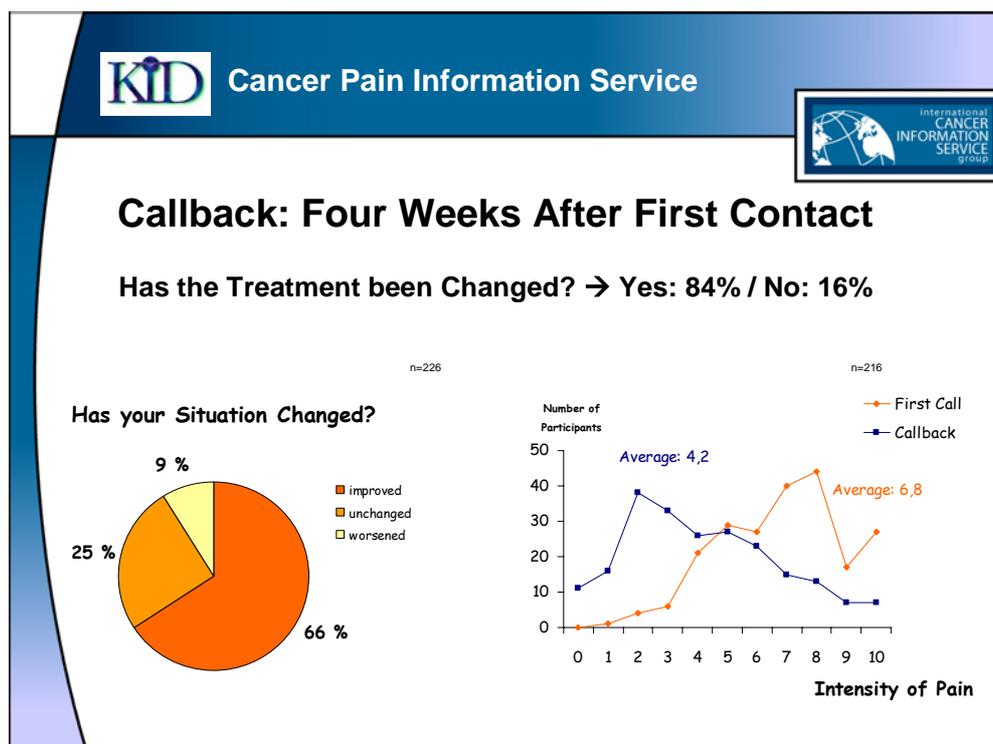
For example, after implementing the breast cancer hotline and gathering data and experience about the special needs of this group, KID was invited by the Federal Ministry of Health to participate in a national working group "Health Aims" - this was a direct way to put patients' interests and needs on the agenda of German Health politics.

The first module was the Turkish service offering cancer information for the 1.5 million Turkish people living in Germany, the largest ethnic minority in Germany.

In 2000 we established a new module for cancer patients suffering from pain. It is financed now by the German Public Health Insurance.

**Cancer pain** management in Germany is still unsatisfactory. The estimated number of insufficiently treated cancer patients suffering from pain is 220.000. 30 to 50% of cancer patients experience pain, about 90% of them are in the stage of terminal disease. According to clinical studies, pain can be relieved satisfactorily in 90% of the patients if the guidelines of the World Health Organization for cancer pain management are followed. The information given by the Cancer Pain Information Service is in accordance with these guidelines. Callers are informed about treatment options and are provided with addresses of specialized treatment centers or physicians and other health care professionals close to their home.

To evaluate the use of the service callers were asked for their permission to be called back 4 weeks after the first contact. This allowed us to compare the intensity of the pain and patient satisfaction with pain management at the 1<sup>st</sup> call and 4 weeks later.

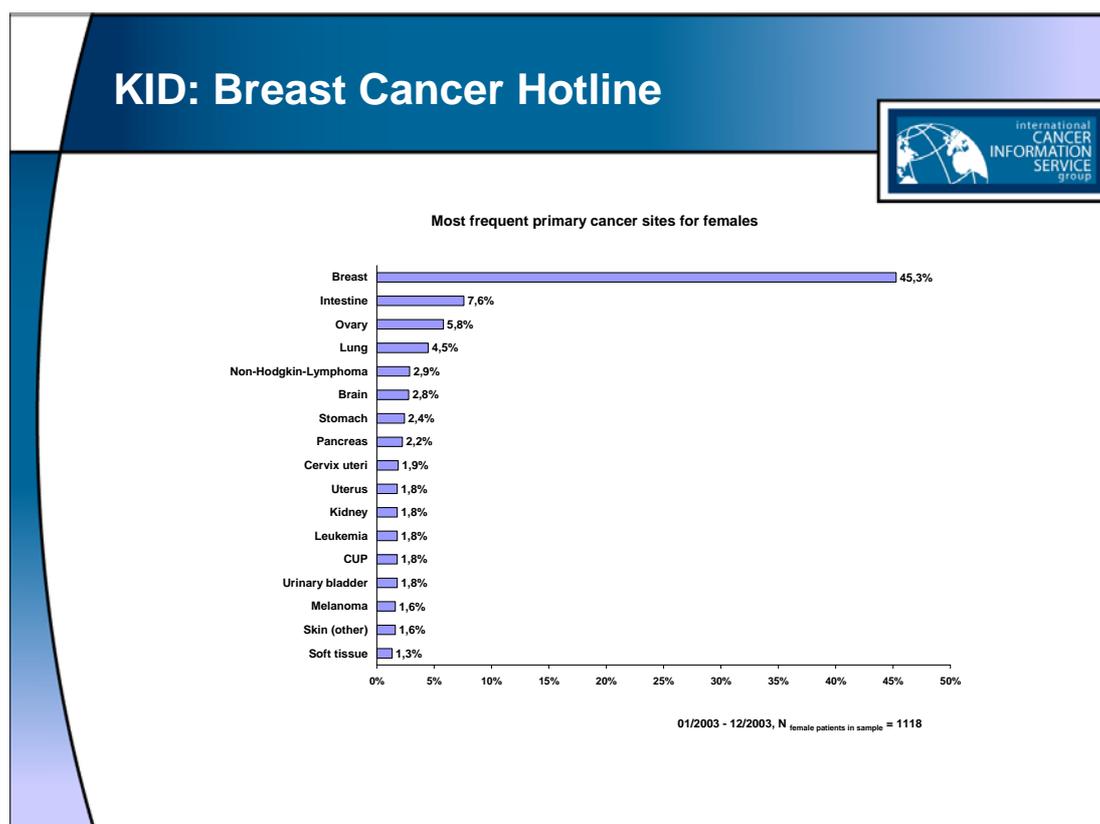


The results show clearly that cancer pain patients do have a benefit from calling the Cancer pain information service, and that a telephone service can definitely improve the situation of this group of patients.

In 2202, two additional hotlines were established:

**Fatigue** is a common syndrome during and after cancer treatment. This hotline offers patients and their families comprehensive information and counselling and helps also to make this syndrome known better. These calls take much more time than usual – between 30 and 40 minutes average.

The **Breast Cancer Hotline** was a very important addition to our service. 45% of all female KID users have questions related to breast cancer, and the majority of callers are female. Overall, inquiries about breast cancer amount to 25% of all calls that reach KID.



The Breast Cancer Hotline was established at a time when breast cancer became the focus of public and political attention, and private organizations and public institutions were interested in funding. KID collaborates in various breast cancer related information campaigns and with women's organizations including an educational visitors' program as an initiative of community outreach.

And last not least the breast cancer hotline allows to provide substantially more women with information – a total of 4.000 through May 2004 – and the detailed evaluation of calls and surveys generate unique data on specific information needs and deficits in care.

On the other hand, only very few women call KID for information about screening programs. Breast cancer awareness in healthy women has yet to be raised. Therefore, KID is an active partner in the national „Initiative for Breast Cancer Awareness“ which informs healthy women actively and in different ways about early detection, diagnosis and treatment options, and at the moment we are exploring ways to offer an additional hotline for breast cancer screening and prevention information with funding by the Initiative for Breast Cancer Awareness.

Integration of all aspects of information goes far beyond hotlines. E.g., many users ask for written information, and this is why KID publishes brochures on topics that either have not been covered yet, or in collaboration projects.

## Publications





**KID Brochures**

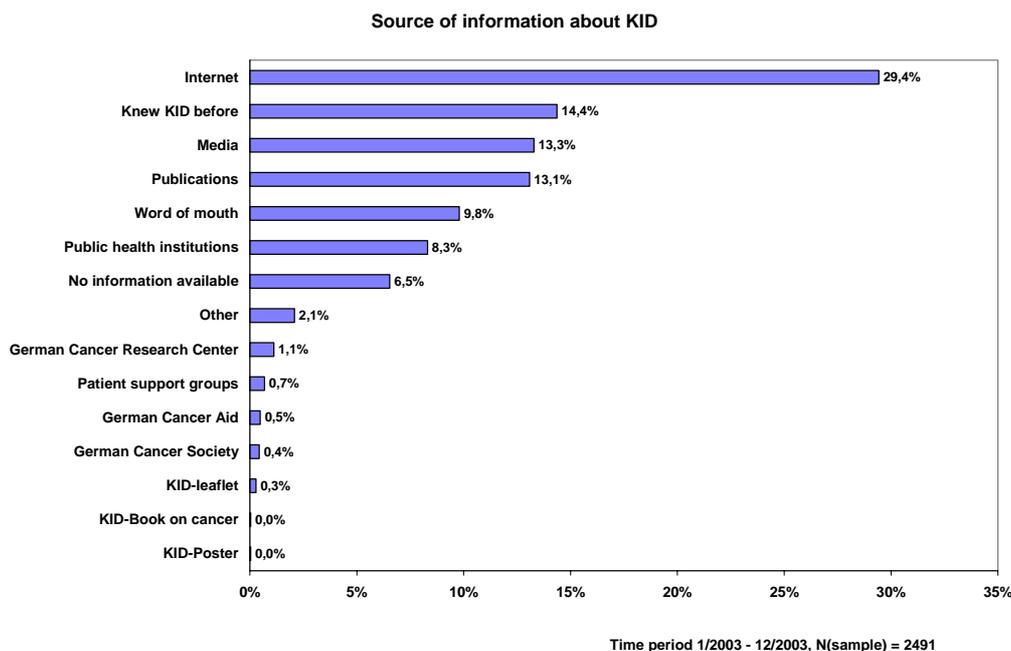
- Breast Cancer
- Bowel Cancer
- Prostate Cancer
- Leukemia
- Lymphoma
- Cancer of the Uterus
- Cancer Pain – what to do?
- Male Cancer Patient and Sexuality
- Female Cancer Patient and Sexuality
- Cancer Prevention
- ABC of Medical Terms
- List of Free Publications for Cancer Patients and their Families

You can find all these brochures on the KID website:  
[www.krebsinformation.de](http://www.krebsinformation.de)

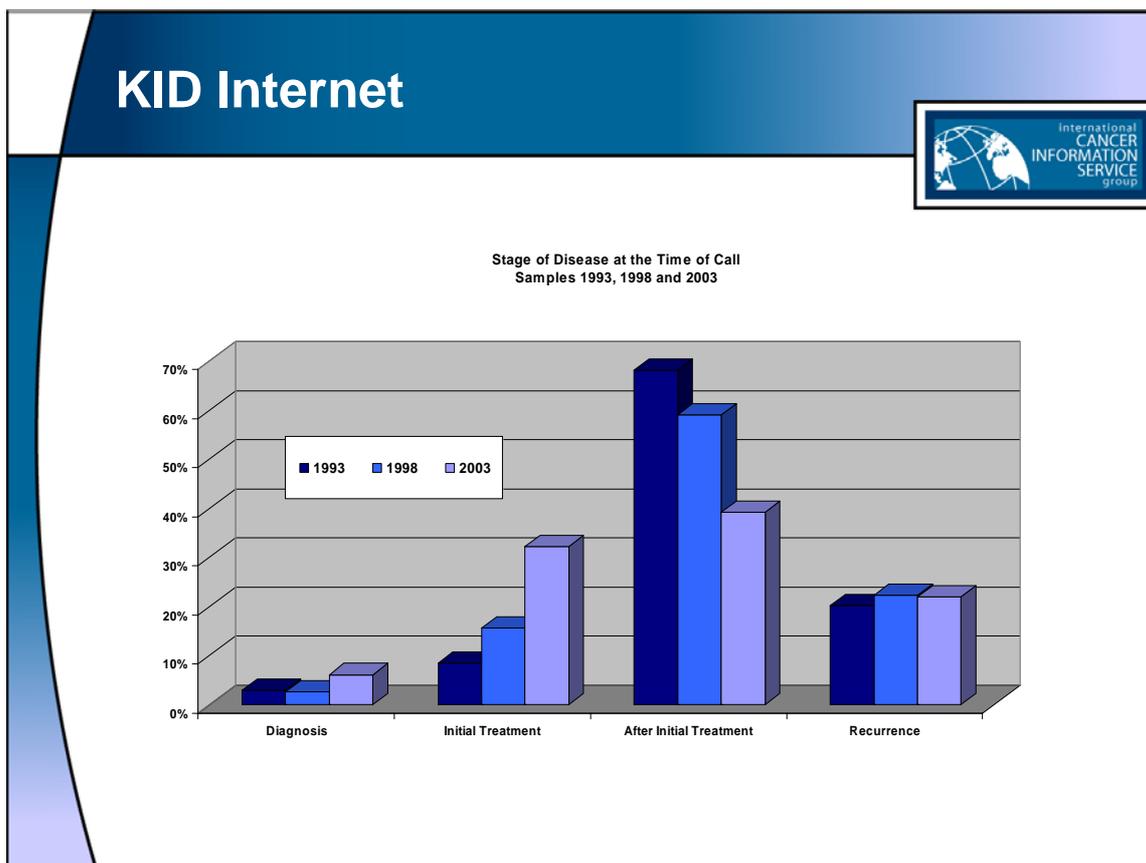
The involvement in collaboration projects is useful because KID can provide information about patients' needs, concerns, their information deficits and also their own personal cancer theories which may cause communication problems.

KID published a number of information brochures and other publications as a supplement to the information given by phone and also to make KID information available to as many people as possible. This was extremely important in the view of the high number of callers who can't get through because of busy lines.

Information seeking behaviour has changed dramatically over the past years, and this is to a large extent due to the Internet. This fact is reflected in our statistics:



Not only say today almost 30% of callers they got the KID telephone number from the Internet, but we also see a big change in that they call at an earlier stage:



Users with a specific case of cancer in the background are very interested in information on living and coping with cancer.

## KID Internet

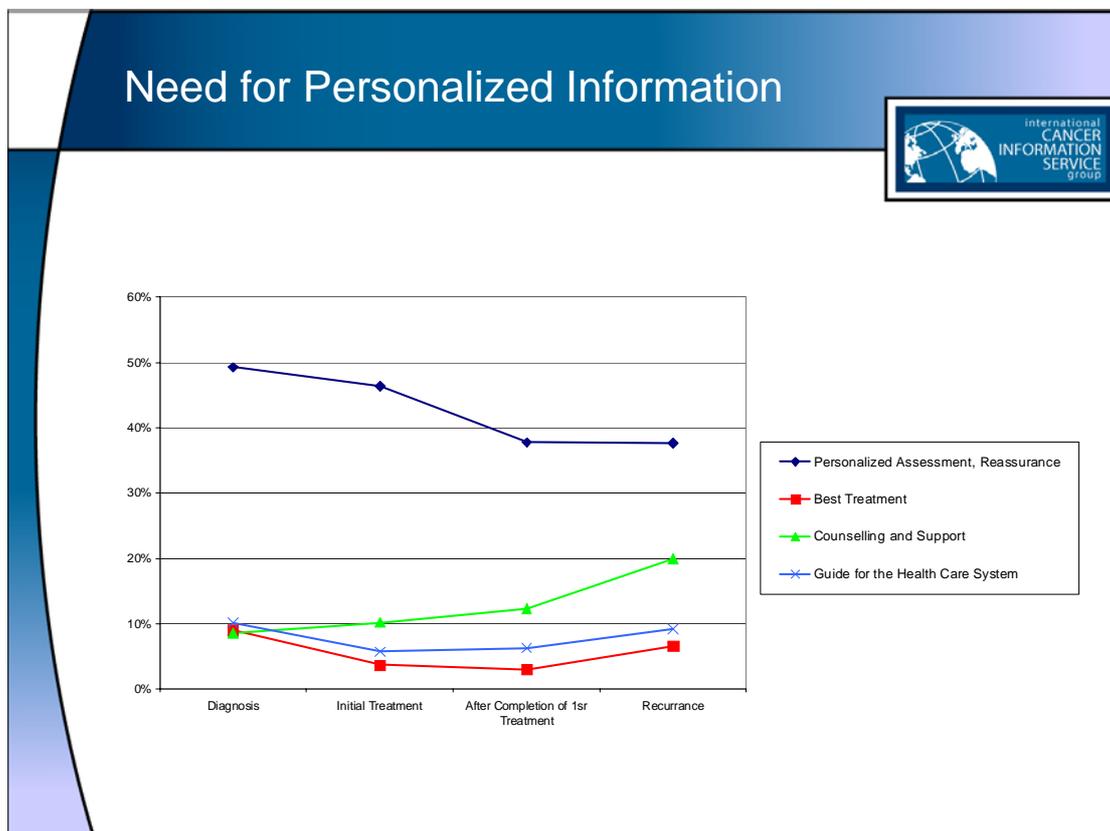


**Internet users who contact KID want:**

- Information on living and coping with cancer
- Information on rare tumors
- To know if the information is accurate, up-to-date and reliable
- To adapt this information to their own situation
- Information by email.

Since March 1999 KID has been offering information on a variety of questions related to cancer under [www.krebsinformation.de](http://www.krebsinformation.de) and is continually adding new information. Beside the efforts to increase the scope of information by KID this enables users to get background information that is more general and supplements the personal dialogue with KID.

Our data show clearly the continuing need for personalized information at different stages of the disease:



## COSMOS

This need, to combine the use of new media with personalized information is at least partly met in a new project that KID is part of.

### KID – Partner in the COSMOS Project

- COSMOS – Community Online Services and Mobile Solutions
- Service for a Virtual Community and Creation of Mobile solutions
- Sponsored by the Federal Ministry of Education and Research
- Project Partners:

Bundesministerium  
für Bildung  
und Forschung

Interdisziplinäres  
Tumorzentrum  
Tübingen

O S P  
Onkologisches Schwerpunkt Tübingen

KID

O<sub>2</sub>

TECHNISCHE  
UNIVERSITÄT  
MÜNCHEN

AOK  
Baden-  
Württemberg

Onco-Connect is the most recent sub-project by OnkoKids: 24 young leukaemia patients who are supplied with a mini computer with integrated mobile phone and camera which contains the most important information about their disease and allows continuous contact with clinic, family and friends. It helps to simplify the administration of appointments and data, gives the patients the opportunity to get in contact with their family, friends and other patients, and it also improves the communication between the adolescent patient and his doctor by email, instant messaging and SMS.

## KID – Partner in the COSMOS Project



Start of a virtual patient support group for

- Breast Cancer Patients
- Leukemia Patients
- OnkoKids - OncoConnect

With

- Quality-Assured Information about Cancer
- Chatroom
- Discussion Forum facilitated by Experts (physicians)
- Partner Matching
- Access through mobile phones / PDAs
- Development of personalized services for Patients (reminder function for taking medication, keeping own medical records)



### Integration of all KID components

All these components and modules are integrated. There is a central data base fed by the scientific staff members to answer all inquiries, whether they reach the main telephone service, any of the special hotlines, or the email service.

Telephone information specialists are being trained to answer inquiries to any of the hotlines, the same training that the E-Mail staff undergoes. All staff members participate in the same oncological training.

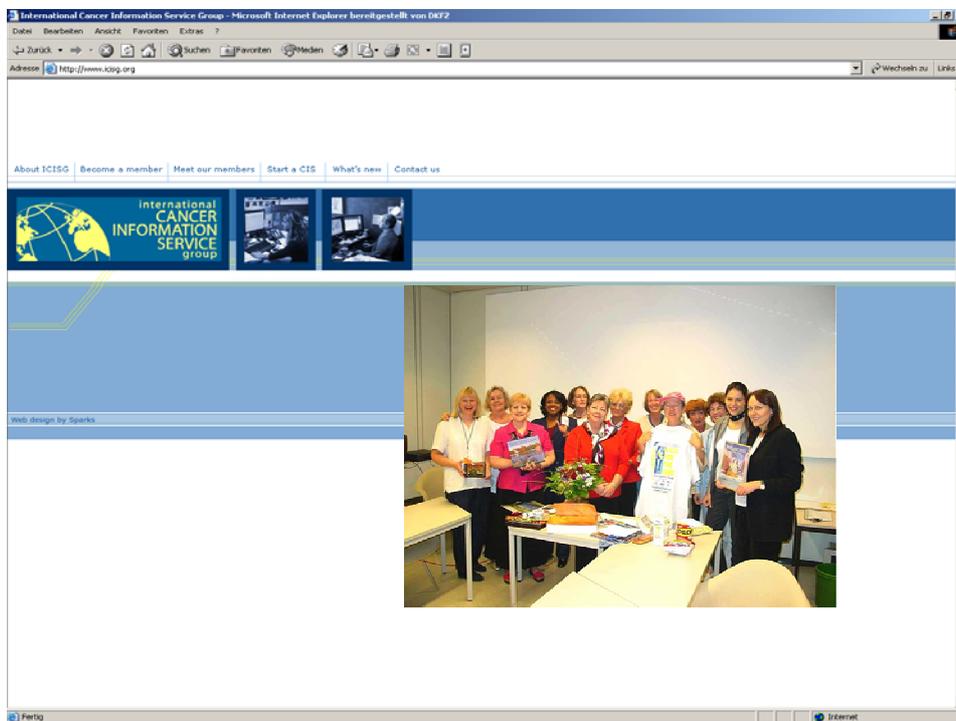
Emails can be answered by the telephone service if users write their phone number.

All brochures are also accessible through the Internet. The COSMOS project allows KID to disseminate information via mobile phones to the Cancer Community.

A Quality Assurance Working Group meets regularly to further develop this integration.

### International Support and Collaboration

We have come a long way. But we have not invented it all by ourselves. Example for KID was the U.S. Cancer Information Service at the National Cancer Institute. Over the past 20 years, the CIS at the National Cancer Institute of the United States has generously supported us with information and know-how which we were then able to adapt to the situation in Germany, and some years later we in turn were able to help new cancer information services in Europe get off the ground. Over the years this partnership has grown and is further strengthened by a staff exchange program between the two services.



*Staff Exchange Program: U.S. NCI/CIS delegation visiting KID in Heidelberg*

Collaboration and support is vital for the success and impact of cancer information services all over the world.

The European network of cancer information services was initiated by KID in 1987, the International Cancer Information Service Group was founded at the 1<sup>st</sup> UICC Global Conference for Cancer Organizations in Melbourne, 1996. It is committed to developing collaboration, sharing information and tools, and to assist and support the development of new services. – And this is why we are here today.