

Spreading the word

How patient groups are delivering life-saving messages to all corners of the globe

→ Peter McIntyre

Cancer patients and their friends and families are uniquely placed to challenge fears and misperceptions that hamper prevention and contribute to late diagnoses, poor treatment and the social isolation of patients. Acting locally but using the Internet to organise globally, patient advocacy groups are extending their support and campaigning work to all corners of the world.

The past decade has seen changes in public awareness about cancer that may be as profound as the changes in treatment. Just as treatment is shifting to a more targeted approach, so too have the voices of cancer become more individual and targeted.

There has been a marked rise in patient-centred groups that reflect the experience of having cancer and the priorities of those who are being treated and who give voice to their concerns and those of their families.

Although there are sometimes disagreements between patient advocacy groups and health policy makers and providers, as these groups have matured, they have generally established good relationships with researchers, the pharmaceutical industry and healthcare professionals with benefits to both sides.

Modern health services have come to recognise that patient advocacy groups provide them with a more authentic voice of patients than they can achieve through other forms of consultation.

Patient advocacy groups are increasingly addressing the public directly to raise consciousness of their special needs. In part this may be a drive to attract funds for research, treatment and care, but it is also to do with building public awareness about cancer, in the hope that a better educated public will lead to greater pressure on policy makers and funders to give a higher priority to their particular area of interest.

While many campaigns are national and focused on improving access and services in a single country, the increase in Internet access enables patients and their groups to share experiences and information globally, and to combine

local and Europe-wide campaigns.

The over-riding mission of Europa Donna, the European Breast Cancer Coalition, is to ensure that all European women have information about and access to state-of-the-art early detection, diagnosis and treatment of breast cancer. It promotes the *European guidelines for quality assurance in breast cancer screening and diagnosis* and works to ensure that national health systems throughout Europe meet these standards.

Member groups in 44 European countries from Albania to Uzbekistan take part in Europa Donna actions. Its central organisation, based in Milan, has a responsibility to raise awareness Europe wide, as their constitution puts it, “enhancing the power of action by European women to gain control of this disease.”

PREVENTION

As part of their advocacy brief, in 2008 Europa Donna launched Breast Health Day (15 October) to reach out to a younger cohort of women to make them more aware of the growing evidence about breast cancer prevention (www.breasthealthday.org).

Susan Knox, chief executive of Europa Donna, and a patient herself, said, “We had been working for a long time on campaigns dealing with the problems of early detection and treatment, primarily with a population of women aged 40 and over. There was a growing body of epidemiological evidence about the

amount of breast cancer that can be prevented by healthy lifestyle choices. There are more than 430,000 new cases of breast cancer in Europe each year. We could avoid and prevent perhaps as much as 30% of these by changing life style.”

On Breast Health Day 2009, Arantxa Sánchez-Vicario, the Spanish tennis star who won 10 Grand Slam titles in the 1990s, joined Europa Donna to launch a ‘Get More Active’ campaign to highlight the 10%–16% of breast cancers that may be due to inactivity. Now in her late 30s, Sánchez-Vicario was chosen as someone who would have a positive impact on younger women throughout Europe.

The campaign was launched with a press conference in Brussels at which Peter Boyle, former Director of IARC, the WHO agency for epidemiological research on cancer, presented the most up-to-date knowledge on breast cancer prevention. Local campaigning was also

Spreading the word. Europa Donna enlisted the aid of international tennis champion Arantxa Sánchez-Vicario (left) and the technology of the ‘e-card’ to spread the message about how important physical activity is to breast health. Pictured with Sánchez-Vicario are the director and president of Europa Donna, Susan Knox (centre) and Ellen Verschuur (right)



WACHHOLDER PHOTOGRAPHY

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carried out in 21 countries to mark Breast Health Day, using pamphlets and posters produced by Europa Donna for its 44 member countries.

The Breast Health Day initiative generated 250 media and blog postings in 22 countries, underlining the impact that a well-planned campaign can have both Europe-wide and in individual countries. From 2010, Europa Donna plans to make the campaign global rather than just European. Susan Knox says, “These important prevention messages can be used by all breast cancer groups as they are applicable everywhere; we would like to help spread them to women and girls across the world.”

This hub and spokes pattern of central support and national groups is also adopted by many of the advocacy groups focused on some rarer cancers.

The Max Foundation supports people with chronic myeloid leukaemia (CML) and their associations. It administers a patient assistance programme to bring the life-saving drug Glivec (imatinib) to people in under-resourced countries. Executive director Pat Garcia-Gonzalez is the step-mother of Max Rivarola from Argentina, who died from CML in 1991, aged 17.

PATIENT POWER

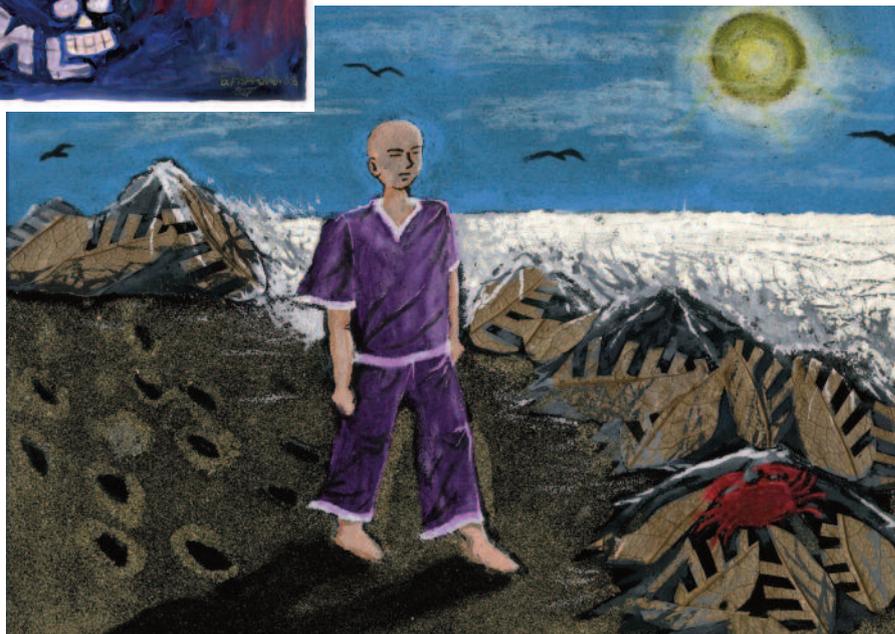
She sees the local groups in countries and individuals who speak out about their experiences as being at the heart of what the Max Foundation does. “Over the past six years we have been very successful in building patient support

meetings and patients' associations in countries where there was no concept of emotional support for cancer patients. We also have now these amazing groups of people who are giving back to the community and living very successful and productive lives and literally changing the face of cancer in their communities.”

In 2007, The Max Foundation desig-



Images of hope and determination. Painted by Diogenes and David, CML patients in the Philippines, these pictures (part of the Max Foundation's Colors of Hope Gallery) make a powerful point about how cancer need not stop you leading a productive life – a message still rarely heard in many developing countries



MAX FOUNDATION

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nated the month of October for a 'celebration of life,' and in 2009 raised the profile of its 'Maximize Life' campaign with a Tribute Wall, where families post uplifting messages, and a Colors of Hope picture gallery where patients and family carers use art to express their emotions (www.themaxfoundation.org).

Pat Garcia-Gonzalez says, "We were at the point where we wanted to do two things. One was for each association to know that there are others around the world in a situation that is very similar, doing the same thing they are doing, and the other is for the world to hear how important it is to have access to treatment in developing countries."

"The literature tells you that CML is predominant in males and that the average age at diagnosis is between 55 and 60 years old. What we found in developing countries is that it was a very young population – young guys of 28 to 30 years old in the prime of their lives. We are using the experience of CML to get people to understand that cancer is a real disease in developing countries and it is very important to pay attention to it."

One key aim is to reduce stigma. "We are working in places where 'cancer' is a very scary word. People get fired from their jobs. Your sister is not able to get married if you have cancer. If you can get even one person who is living a very productive life with cancer to get out there and start saying that, then we are changing the way that cancer is perceived. People will be more willing to go to the doctor and that this may lead to early detection and more likely good clinical outcomes."

As an alliance of support, advocacy and information groups for brain tumour patients and carers in different countries,

the International Brain Tumour Alliance (IBTA) also recognises country groups as a crucial element.

Co-directors Denis Strangman and Kathy Oliver helped form the IBTA out of personal experience. Denis' wife Marg died of glioblastoma in 2001, while Kathy's son has lived with a brain tumour since diagnosis in 2004. Kathy Oliver believes this shapes the organisation. "Everybody who works for the IBTA is a volunteer, including the two directors, and has hands-on experience of the brain tumour journey, either as caregivers or relatives."

TREATMENT AND SUPPORT

Kathy points out that many messages central to combating other cancers are not relevant for the 200,000 people a year worldwide who develop a primary malignant brain tumour. "I don't wish to take anything away from these campaigns, but in the case of brain tumours, prevention, screening and lifestyle issues aren't relevant. They attack anybody from tiny babies to the elderly. There is no way you can prevent them because nobody knows what causes them and screening is unrealistic, so it really needs a strong focus on treatment and support."

"The dire prognosis and lack of funding for research, together with misdiagnosis and delayed diagnosis, make this an extremely tough disease."

In 2007 the IBTA launched its 'Walk Around the World' event, with sponsored walks in dozens of countries before or during International Brain Tumour Awareness Week in the autumn (www.theibta.org).

The IBTA encourages the establishment of brain tumour patient support

groups in countries where they don't exist. It worked with emerging groups in Zimbabwe, Hong Kong and Lithuania that gain greater awareness through activities like the World Walk. In Zimbabwe, where 180 people joined the walk, Christine Mungoshi, director of the Zimbabwe Brain Tumor Association, appeared on television. She said, "It was a true awareness raising event, as many people were not aware of the impact of brain tumours and also the existence of our organisation."

In one Asian country a philanthropist who had a family member recently diagnosed with a brain tumour saw the walk taking place and immediately offered funding for a brain tumour centre.

The strength of the global coalition is reflected in the World Walk project. In 2009, 182 organisations around the globe supported the World Walk and International Brain Tumour Awareness Week. In total, 38,114 participants in 13 countries walked 226,590 kms, the equivalent of five times around the world at the Equator. They raised the equivalent of 2.5 million euros, all of which is retained by local groups for local brain tumour charities and research organisations.

These organisations don't always have the same priorities. "We recognise that every country is different culturally and that resources vary," says Kathy Oliver. "We encourage and network with them. We don't push a particular message when we know it is not going to be relevant in that country."

The Max Foundation too exceeded its target for this year. It aimed to collect 1000 messages on the Tribute Wall during October, and succeeded in collecting 1500 messages from 54 countries.

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BRAIN TREKKING, HONG KONG



They worked successfully in India, Malaysia, the Philippines and Chile and made contact with new groups in Mauritius, Cameroon and Azerbaijan. The Henzo group in Kenya organised an event in Nairobi and invited the media and people from the community, and launched themselves as a CML patients' association. "It became something very exciting for us to start to put together this movement of people changing the face of cancer in developing countries," says Pat Garcia-Gonzalez. "I think that the main benefit is that many of these young patient associations in countries where we campaign are able to get visibility."

THE INTERNET AND SOCIAL NETWORKING

All these organisations have used the Internet and social networking sites to great effect.

A global event for local benefit. The Walk Around the World concept, developed by the International Brain Tumour Alliance, neatly links locally organised sponsored walks to the global goal of collectively covering enough ground to encircle the globe – pictured here is the 2008 'brain trekking' walk in Hong Kong

The Europa Donna Breast Health Day website (breasthealthday2009.org) features an attractive 'e-card', which combines information about the key health benefits of exercise with some clever graphics of bouncing balls – representing both various breast sizes and various sports activities – and a catchy tune. You can send this by e-mail to any woman to encourage them to become more active; the 'e-card' also encourages the recipient to then forward the message to her own friends.

Between October 2009 and the end of the year, about 5000 e-cards were forwarded in this way to women in 58 countries and many more were sent out directly from the site.

"The e-card to me is one of the most exciting aspects of the programme," says Susan Knox. "Younger people today are really learning through interactive websites so we felt that this would be attractive to younger women and a way for them to communicate with each other. It enables us to reach out with important messages to women across the globe."

Kathy Oliver is also enthusiastic about the potential of new technology to increase the power of campaigns. "We keep finding more organisations each year because more and more people hear about the walk. I don't know how we all survived without the Internet in terms of communication. People read about things

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on the Internet and want to do it themselves. We have people contacting us all the time saying, ‘What a great idea, I would like to organise this.’ It gathers its own momentum.”

The Max Foundation not only uses a website to host its picture gallery and Tribute Wall but also has its own Facebook page to publicise its campaigns. Pat Garcia-Gonzalez says, “We like to use human power, but we don’t believe you have to spend a lot of money to do a campaign. A lot of it is about giving a little bit of funding to the groups in the country to organise this event. I think we gave a total of around US\$ 15,000 (11,000 euros) to put together 40 events in 22 countries.”

However she has a word of warning about relying too heavily on the Internet and social networking. “One of the big lessons we learned was if you want to do a campaign in countries where access to the Internet is not so broad you have to use a combination of low tech and high tech.

“In these countries, we created a real wall where people put their messages on paper and then we put them onto the Internet. You have to be able to have someone on the ground working in a very old-fashioned way.”

THE FUTURE

Breast Health Day will continue as an annual event on 15 October 2010 and beyond, and Europa Donna plans to extend its prevention campaign globally next year. However, in-depth evaluation will be also be needed, says Susan Knox. “The amount of money we have to spend

on a campaign like this is very minimal. The World Health Organization and the European Commission have major prevention programmes, and I would hope that eventually we can link our project with one of these. Otherwise it will be extremely difficult for us to do the kind of studies we would need to measure the impact our programme is having. How many people are changing their lifestyle and how many are even seeing the messages? Those are key questions that need to be answered.”

The CML Awareness Campaign will also continue, and The Max Foundation too is looking to combine efforts with larger cancer organisations to reach patients who are under-

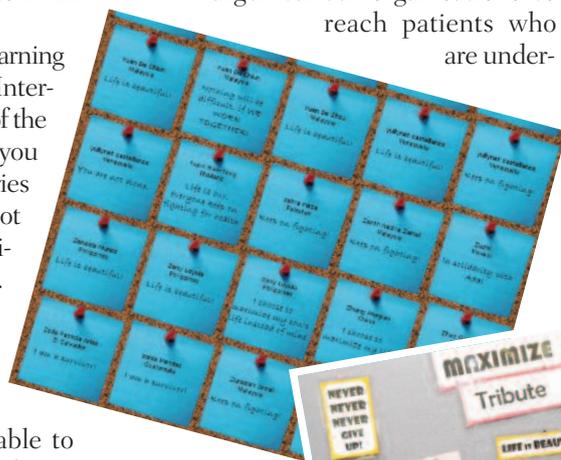
served. Pat Garcia-Gonzalez says, “We hope to get a little bit more visibility globally, but I am primarily interested in reaching each and every person who can benefit from treatment for CML.”

The Walk Around the World event will step out again in 2010 – IBTA Awareness Week will be from Sunday 31 October to Saturday 6 November. It is a tool, says Kathy Oliver, both to support individuals and to help change the face of treatment and support.

“When my son was first diagnosed, I knew nothing about brain tumours. My immediate feeling was that we must be the only people in the world who have this problem. Through coalitions like the IBTA and the many excellent brain tumour patient groups around the world, people with a rare cancer like a brain tumour can be comforted by the fact that they are not alone.

“In a relatively short time since, we have seen a greater focus of attention not just on brain tumours but on other rare cancers too. There is still a tremendous amount of work to do in these areas, but we are witnessing the emergence of more targeted therapies, genetic profiling and other cutting-edge aspects of treatment which appear promising.

“What’s more, we are seeing increased collaboration on a global scale not just with patient groups but with the scientific community as well – and that is a very powerful direction.”



Different cultures, same message. The virtual wall of hope (top) offers a space for communication and solidarity for CML patients and their families with broadband access. Real walls of hope, like this one in Malaysia, are more relevant in many settings (themaxfoundation.org)

