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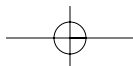
Education & knowledge through people & facts

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Michael Stevens

→ Michael Stevens: caring for the whole child → How can Europe afford the best for all its cancer patients? → Don't look away: survivors of head and neck cancer need expert support → Learning to care: the European School of Oncology celebrates its first 25 years





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Michael Stevens: curing the whole child

→ Marc Beishon

When paediatric oncologist Michael Stevens talks ‘grades’ with parents, he is as likely to be discussing their child’s schooling as their cancer. If young patients are to have a future, you must look at their life as a whole, he says. He wants greater support for survivors and more research to predict which patients can safely be spared the most aggressive protocols.

Children with cancer are constantly in the public eye as subjects of intensely emotional documentaries and fund-raising activities. Few other health topics have so consistently been profiled in recent years, not least because of the dramatic breakthroughs in cure rates achieved since the 1970s.

This attention is a paradox for Michael Stevens, professor of paediatric oncology at the University of Bristol in the UK and an authority on childhood soft tissue sarcoma, with a long track record of organising paediatric oncology services.

“We see only about 115 new patients a year in Bristol – about 10% of the country’s workload in childhood cancer – and there are probably no more than 100 children a year in the UK who have my particular specialty, rhabdomyosarcoma,” he says. “I spend my professional life worrying about service provision for a relatively small number of kids and I’m conscious of how many other issues there are that a paediatrician could be addressing with scarce healthcare resources, particularly in the developing world.”

It is perhaps both a modest and accurate assessment, and one informed by his earlier work in

nutrition and sickle cell disease in Jamaica, but Stevens in no way diminishes the achievements made by paediatric oncologists. “We’ve moved from a position where we really couldn’t do much for children with cancer to 90% cure rates for some diagnoses. Today, one in every 800 young adults in the UK is a survivor of childhood cancer.” Yet it remains the leading cause of death from disease among children and teenagers in the developed world, and there are a special set of issues for teenagers and young people that are concerning oncologists.

When it comes to promoting the interests of paediatric oncology in the far larger world of adult services and research in the UK and Europe, Stevens has in recent years also played a major role. In 2000, he became president of the European branch of the International Society of Paediatric Oncology (known as SIOP). This had been formed two years previously, largely to strengthen the role played by paediatricians within the Federation of European Cancer Societies (FECS – where he is the current treasurer), and to integrate the paediatric oncology effort in Europe, which was far less organised than in North America, particularly in research.

“Yes, children with cancer are different from adults with the disease, but our specialty still needs



HORST FRIEDRICH/CONTRASTO

“Paediatric oncologists need to make their voice heard much more strongly”

to be seen in the totality of cancer care,” says Stevens. He notes crucial issues that are greatly affecting paediatric oncology, such as the impact of the European Clinical Trials Directive on academic research, and the availability of novel drugs, while the specialty is also at the sharp end of the need for genuine, high-quality multidisciplinary working.

He also points out that paediatric oncology has pioneered, and continues to lead, in major steps such as first use of combination chemotherapy,

the discovery of the first cancer gene (implicated in retinoblastoma), and now modern research such as the use of minimal residual disease technology to guide therapy in children with leukaemia.

Despite these achievements, Stevens believes paediatric oncologists need to make their voice heard much more strongly if the specialty is to build on the great gains already made. “My fear is if we are not visionary enough we will find that improvements in, say, treating breast cancer will

“People didn’t expect children to succeed in school after being treated”

eclipse our achievements.” This is not about competition but about organisation and resources to find answers to key questions, such as why 30% of children are not being cured at present.

In particular, he worries that paediatric oncology may lose its attraction as a career choice, because it is still a relatively small specialty and of less interest to investment by the pharmaceutical industry – and medical students are more commercially minded these days.

That wasn’t an issue for the young Stevens, who is the only one of his family, past and present, to go into medicine, and it was a year out shortly before graduating from medical school that first introduced him to the type of practice he knew he wanted to pursue. “I went to work in a nutrition research unit in Jamaica, which showed me that paediatrics offered a blend of social and personal interaction and scientific discovery – and paediatric oncology is the same. I don’t think I’d have been a good pathologist.”

Working in adult general medicine in the UK, he was asked to see a 14-year-old boy with a brain tumour who had gone blind after radiotherapy. “My task was his endocrine care, but I remember him well. I found him very challenging and it was like a light bulb going on – and I made my move towards paediatrics and oncology.”

Stevens made great use of fellowships – another spell in Jamaica followed, this time to work in a sickle cell project. He was one of the first paediatricians to be involved in the project, which was funded by the UK’s Medical Research Council and run by the “very dynamic” Graham Serjeant at the University of the West Indies. This gained Stevens an MD and his first major taste of clinical research.

He also held two fellowships at Toronto’s Hospital for Sick Children. “There were few systematic training opportunities in paediatric oncology in the UK, and Toronto was a different order of magnitude in size and structure to the hospital in Oxford I was then working at. It was a two-way trade – I offered

my sickle cell disease experience to Toronto’s division of haematology and oncology, but really I was absorbing knowledge like a sponge.”

He worked on staff for a short while at Toronto, but returned to the UK to seek a consultant’s post in paediatric oncology, and after writing to many departments he landed a job at Birmingham Children’s Hospital, where he worked for more than 15 years alongside Jill Mann, a well-known British specialist. “I chose to specialise in solid tumours rather than leukaemia. It was the early days of forming the subspecialties we see now, and momentum for improving cure rates was building.”

Highlights for Stevens were helping to set up a brain tumour service and building a multidisciplinary approach with people such as specialist nurses, dieticians, play leaders and psychologists. “We did a lot of work on changing attitudes to schooling – people then didn’t expect children to succeed in school after being treated. But our view was that if children are to have a future you need to ‘cure’ the totality of their life. You are doing them a disservice if there is no life at the end of their treatment.”

British children’s hospitals such as Birmingham and Bristol have been among the forerunners of family-centred care and multidisciplinary working, and Stevens would like to see this approach promoted more widely across Europe. One way this is happening is through a joint SIOP/EONS (European Oncology Nursing Society) project, funded by FECS, which is helping doctors and nurses to work together better. “There’s no room any more for the old fashioned view of doctors dominating and coordinating care – in my view it is the senior nurse who often has the best skills to work alongside children and their families, as unlike doctors they are always present on wards.”

It is certainly true that some European hospitals have been slow to make special provision for children, with few or no tailored inpatient facilities, and rules restricting personal belongings and barring parents from spending the night with their child. “An Italian doctor who worked with us at Bristol for a few

weeks expressed surprise at the amount of stuff the families bring with them. We want them to feel comfortable but we do have to make sure we have an environment where we can safely nurse a child. I've been to some hospitals on the Continent that seem rather clinical to me – but I'm not sure what the right balance is.”

With evidence pointing to less need for measures such as protective clothing in places like bone marrow transplant units, Stevens is happy that there is a good deal more contact on the wards than once was the case, but with the UK's current poor record on infection control he says parents are understandably very concerned.

“You can't be a good paediatrician without listening to parents – not just of individual children but parent groups as well,” says Stevens, adding that an achievement he is particularly proud of is helping to set up a national parents' organisation for children with cancer. “We now have parents participating in national policy making as well,” he notes.

The parents' group is one of several committee and health leadership roles that Stevens has taken on. He feels strongly that senior doctors need to be engaged with service delivery and policy making. “In Britain we all have a degree of ownership in our health service – I am disquieted by doctors who decide unilaterally what is best for their patients. You can't make all your own decisions, as we work in a resource-limited environment. How can you manage a healthcare system if doctors won't engage with it?”

At Birmingham, Stevens rose up the ranks to become medical director of the children's hospital – a senior executive position in the UK's National Health Service (NHS) – where he found out just how difficult such a job can be. Not only was he responsible for transferring clinical services to a new location at one point, but he also became embroiled in one of the worst ethical storms to hit the NHS, when it was discovered that children's hospitals had retained organs for research without parental consent.



BRISTOL ROYAL HOSPITAL FOR CHILDREN

“I had to deal with parents' support groups and, at times, a very aggressive media. I did a lot of interviews with distressed parents – as a paediatric oncologist you are used to difficult meetings, but some of these were quite the worst I've had. Some parents were very angry, although some had enormous dignity, and for others we were able to offer comfort for years of unconsolated bereavement, so it wasn't all bad.” The EU Tissues and Cells Directive, and in the UK, the Human

Child-friendly by design. Bristol Royal Hospital for Children makes great efforts to bring home, family and play into the hospital environment

He feels strongly that senior doctors need to be engaged with service delivery and policy making

“We have shown it is perfectly feasible to carry out a lot of care in a child’s own locality”

Tissues Act, have brought much needed regulation to this fraught topic.

Stevens left Birmingham, where he was primarily an NHS consultant, to take up his academic position at Bristol – an endowed post funded by the CLIC Sargent children’s cancer charity. It was unusual to make such a move at his level. His current position, of course, still carries clinical as well as teaching responsibilities, and he found the clinical side rather less smooth running and more complex than at Birmingham. “We have developed a model we term ‘shared care’, where we spread care out to localities over a wide area of south-west England. I’ve spent a lot of time building up networks and ensuring that the correct policies and procedures are in place, and we have shown it is perfectly feasible to carry out a lot of care in a child’s own locality. It’s a model promoted by our National Institute for Health and Clinical

Excellence [NICE] and I hope it will be taken up more widely in the UK and Europe.”

Stevens has also been chair of the UK Children’s Cancer Study Group (now known as the Children’s Cancer and Leukaemia Group), which is 30 years old – its main remit is organising clinical trials. It was through this group that he also found time to develop his research interest in soft tissue sarcoma. “I had no particular knowledge of this until I was asked to take on the clinical trials portfolio for the subspecialty. There was no real direction then for managing children with soft tissue sarcoma and we were borrowing strategies from the US – but I found there were clear differences in treatments between the US and Europe, particularly France, and after visiting European colleagues we decided to align ourselves with them.”

One of the main differences has been in the use of radiotherapy for children with rhabdomyosar-

Play time. This young patient at the Bristol Royal is about to insert a Hickman line into a sick teddy bear. Play specialist Sam, who is supervising the operation, is funded by the CLIC Sargent children’s cancer charity



CLIC SARGENT

coma. “If you use radiotherapy on sites such as bladder and head and neck, you can damage kids in the long term, and the Americans had a policy of using radiation for almost all cases. Our work in Europe has shown we can predict groups where radiation is not necessary, but the downside may be using more chemotherapy. We are influencing the Americans – but the argument has been going to and fro for some time. It’s an iterative process.”

It is a process common to other fields in oncology, but as Stevens points out, the relatively small numbers of paediatric cancers places extra challenges on obtaining timely results from research. Wide and well-organised collaboration is crucial. In the case of soft tissue sarcoma, Stevens and colleagues had first to “hammer out what seem like simple things but are fundamental – definitions, how you report results, prognostic factors.” But entering enough children in large trials remains a problem in Europe.

As an aside, he notes that paediatric oncologists tend to be very well organised people as a result of pursuing collaboration – and often make good administrators. “I also took time to learn working French to communicate better with colleagues in France – it’s hard enough being seen as the token English person.” He now numbers collaborators such as Odile Oberlin, at the Institut Gustave Roussy in Paris, Modesto Carli at Padova, and José Sanchez de Toledo in Barcelona among his closest colleagues and friends.

Given his organisational background, it was no surprise when Stevens was asked to step in as president of SIOP Europe, where he set about two priorities for the paediatric oncology cause. “The first was elevating SIOP’s position in FECS, where in all honesty we had not been playing a proper role, although we had board representation. A lot of paediatric oncology colleagues have seen FECS as irrelevant – but I didn’t. If there is an organisation for all cancers it is incomplete without us. My position is if you join something you should contribute as well as you can.”

The second aim was establishing a clinical research structure that should, given Europe’s size, at least rival if not surpass the much more organised Americans. “It just does not make sense, for example, that we have three separate collaborative research groups in soft tissue sarcoma in Europe. If we could harness all researchers we could learn so much faster. For example, I’m just now writing up a trial that started as far back as 1995. The main way to speed things up would be to increase the size of population we work with.

“We have to be realistic about the speed at which national groups want to move, and the different resources and legal frameworks among the countries. However, we are getting people to talk about the issues.” Progress has been made, meanwhile, in less contentious areas such as a paediatric oncology training programme and getting more ‘floor time’ for the specialty at events such as ECCO (European Cancer Conference), where there was little exposure before, he comments.

Fostering SIOP’s relations with FECS, says Stevens, has been very beneficial to these ends. With few funds of its own, Stevens negotiated an agreement for FECS to host SIOP’s secretariat, and the two bodies have jointly lobbied the European Parliament on concerns such as the impact of the European Clinical Trials Directive and the overall needs of children and young people with cancer.

In time Stevens is hopeful that SIOP will realise its ambition to unify European research in paediatric oncology in some form, at least by agreeing more common international protocols. As he adds, there is no other moving force – the EORTC (European Organisation for the Research and Treatment of Cancer), an obvious candidate, currently plays only a relatively small role in child cancer studies, through its children’s leukaemia group.

Along with the challenge of increasing the pool for collaborative research, Stevens adds that more attention needs to be paid to the nature of trials. “Most clinical trials are about survival rates – but maybe we can’t drive cure rates any higher in some

“It makes no sense that we have three separate research groups in soft tissue sarcoma in Europe”

“We need more equivalence trials where we reduce or remove some aspects of treatment”

conditions and it is possible that we might be overtreating some kids,” he says. “We need to do more studies that are equivalence trials where we reduce or remove some aspects of treatment.”

It’s a topic that’s entwined with work he is doing on quality of life and long-term effects. “I see young people in the their late teens who may have been treated when they were just two years old – they have no memory of their disease and the angst it caused their parents. They may be facing infertility, risk of heart problems or physical difficulties, and of course there is also the risk of another cancer. They

do need information and support, but there is little structured clinical provision for this growing population of young people.”

As he adds, if you have diabetes as a child you transition into an adult diabetic service, “but you can’t into adult oncology because you don’t have cancer any more. There is some research on care models for this group, but much more needs to be done.” A balance also needs to be struck between the need for collecting data vital to understanding late effects in populations – which can be many years later, and is being done in large cohort studies – and the stress on individuals of follow-up (see also *Cure at what cost?* by Stevens, EJC 41:2701–2703).

At European level, the future of FECS is important to these paediatric oncology issues and, as the current treasurer, Stevens is optimistic. Certainly he recognises the huge upset caused by the withdrawal of ESMO (European Society for Medical Oncology) as a result of a decision by FECS to become a wider membership organisation. He’s also seen a number of ‘big egos’ at work. But he says a plan to rebrand under the ECCO name at this year’s flagship conference should go ahead. “No one knows what a ‘federation’ means – politicians and patients groups have been telling us we have to talk with one voice.” He will not though be staying on the FECS/ECCO board – but admits he might have aspired to take a leadership post if he thought a paediatric oncologist could hold sway with the membership in the current climate. “I do hope others will have formed a better view of the specialty though.”

Stevens is also one of the founders of the controversial Cancer United initiative, and concedes that the early publicity about links with Roche was damaging. “But no one could argue with our aim of promoting cancer plans across Europe. That work programme got delayed, but we now have financial support from other sponsors and have located the secretariat in the FECS office, where I’d like to see it become one of the main political activities of FECS/ECCO, which has been a major weakness.

MORE OFF-LABEL THAN ON

There are relatively few drugs available to treat childhood cancer patients compared to adult patients, and of these many are actually adult drugs still not authorised for paediatric treatment, despite a very long history of clinical use. The proportion of children entered in trials is much higher than in adults, but the Clinical Trials Directive has compounded the difficulties of resourcing research into new therapies. “That’s because much of our research is funded by charities and government,” says Stevens. “Most of the new targeted therapies are being designed to meet the characteristics of adult tumours. There has been no economic case for pharmaceutical companies to research targeted drugs for children for cancers such as rhabdomyosarcoma – but we would dearly love to see new agents.”

There is promise that agents such as bevacizumab (Avastin), currently in adult use, will ‘trickle down’ to paediatric use, but new this year is a paediatric regulation from the European Union that aims to stimulate the development of child therapies by measures such as requiring drug companies to include paediatric data when seeking approvals, and extensions to patent protection. The regulation also aims to ensure medicines are properly tested and administered to children – correct dosage has long been a problem throughout paediatrics. It is too soon to say precisely what the regulation will mean in practice. “I hope we don’t have to gain retrospective approval for drugs we already use routinely, at least not without financial help for the necessary studies,” notes Stevens, who adds, “I’ve spent most of my career prescribing drugs that have not been licensed for children – but I don’t lose any sleep over it. That’s the nature of paediatrics, but this new legislation is good news.”



Children sans frontières. Two years ago Stevens did a sponsored bike ride, to raise money for an orphanage in Karnataka, India. Having started his career working in nutrition and sickle cell disease in Jamaica, Stevens is painfully aware of how much paediatricians in poorer parts of the world could do with the sort of resources he has at his disposal in the UK

I remain committed to doing what I can to help.”

Helping to develop the next generation of senior paediatric oncologists is also part of Stevens' work. Despite the emotional context of working with children, and the possible lack of kudos, he says there is no shortage of doctors wanting to enter the specialty in the UK. “We also had to turn people away from the first ESO [European School of Oncology]/SIOP masterclass in paediatric oncology held in Italy last year,” he adds. “Most don't go into this field unless they are sure it's what they want to do, although I am concerned that in the UK there is less opportunity for young doctors to get a 'taster' of specialised areas in paediatrics with the way training is now organised.” As he currently chairs the university's medical education committee, and is also director of the university's Institute of Child Life and Health, he's well placed to make sure paediatrics gets a fair hearing at Bristol.

Stevens is a parent himself – although his three children are now grown up and he enjoys life in a quiet village near Bristol with his wife Sue, who is a Church of England vicar, and dog Nellie (great for letting off steam). “I don't really have any hobbies –

I am aware that perhaps I identify myself too much through work.”

A forthcoming sabbatical will allow some more time for himself and his family, and after that any thoughts of early retirement have been postponed in favour of new challenges. “I want to develop more academic research at Bristol – not just my own soft tissue work, but establishing new work on the epidemiology of cancers, why some kids contract the disease and why some respond better to treatment than others. I also want to evaluate properly our national care guidance for children to see what difference it is making to service delivery.”

On the European front Stevens is keen also to play a roving role in helping countries to establish and assess their child cancer programmes, especially in eastern Europe, in line with the aims of Cancer United. He's already done that in New Zealand in 1999, and has also been scientific assessor to a large paediatric oncology unit in France.

The number of local childhood cancers may thankfully remain small – but the opportunities to bring care standards to a much bigger stage are growing.

How cancer hit the Romanian political agenda

→ Jim Boumelha

Romania's forgotten cancer patients erupted onto the public scene when they staged a demonstration outside the Ministry of Health in May. Things will never be the same again...

When cancer is taboo, patients suffer – not least because health systems can get away with ignoring their needs. This has long been the case in Romania, where spending on cancer is reported to account for around 0.3% of the health budget, compared to figures like 4.8% in Germany, 4.7% in Sweden, and 3.9% in the Netherlands and the UK. But things are finally changing.

After years of battling to get cancer onto the political agenda, a federation of patient and advocacy groups hit the headlines in May – and not just in Romania – when a small but determined group of cancer patients besieged the Ministry of Health as their representatives went inside with a list of demands:

- Give immediate access to treatment for all cancer patients
- End the bureaucratic obstacles patients face in getting the go-ahead for their treatment, and provide written justification when any treatment is refused
- Introduce transparency into the public health regulations
- Set up a cancer registry to recognised standards
- Allow free access to supportive treatments and breast prostheses
- Give all patients access to care by specialists – including trained medical oncologists

- Prepare a national cancer plan covering everything from prevention to rehabilitation

After two hours the patients chalked up their first victory. They were given two seats on a revamped Oncology Commission – a body set up by the government that brings together patients, oncologists, government officials and health insurers. Marlene Farcas is director of the Societatea Romana de Cancer, one of the advocacy groups supporting the protest. She believes this step marks a real change. “This commission is not just a talking shop. Its brief ranges from access to drugs to re-equipment of hospitals, training of oncologists and cancer registries.”

Florin Băcanu, an oncologist who has been newly elected onto the Commission, says the patients' protest was enormously important in helping to usher in a new era of democracy in decision-making – and not just in patient representation. “For the first time, oncologists were able to vote freely for their representatives without undue influence.” He is unhappy that hospital-based oncologists are over-represented, but says this is nothing compared to the old times when only professionals who were politically involved would get access to the decision-makers.

Members of the Oncology Commission have a huge task ahead of them. According to official estimates, out of the 400,000 patients diagnosed with cancer, only 76,000 are currently in treatment – a



Top: Corina Alexandru, president of the Asociatia Oncologicrom in Constanta, talks to the demonstrators. Middle: Health Minister Eugen Nicolăescu comes out to talk to the press. Bottom: Cezar Irimia, vice-president of the Romanian Federation of Cancer Societies talks to a policeman whose mother is on the

demonstration. Alexandru and Irimia were among the five-strong delegation that met the Minister. Irimia was elected as one of the two patient reps onto the revamped Oncology Commission



reflection of the tiny proportion of the health budget spent on this disease. Every aspect of cancer treatment is in a grim state – access to drugs is poor, equipment is out of date and worn out, specialist training is limited to doctors in a handful of cancer centres, and a significant section of the poorest population has almost no access to free healthcare. Worse still, there are no systems in place for collecting and analysing the data necessary to get a grip on the situation.

The Commission has hit the ground running. Farcaș is impressed at the way it has got down to business in its first two meetings, mapping out a strategy for improving cancer treatment, and she welcomes the spirit of cooperation among its members – including health officials and representatives of the national health insurance agency. “The plan in general is done,” she says. “They know what they have to do and the Ministry agrees to what they have to do. But it needs time to be organised.”

A QUESTION OF MONEY

Băcanu is more cautious, and reckons that all the plans on paper, however welcome, will only become meaningful when the government agrees to back them

with hard cash. He accepts, however, that early progress has been made on some important issues such as the setting up of cancer registries. “Having agreed that the cancer registry starts from the GP [general practitioner], it was not difficult for the ministry to agree to give every GP a computer so they can set up a database and transmit the results,” he says.

But many other core issues detailed in the protesters’ list of demands, such as access to drugs and the training of oncologists, are likely to prove harder nuts to crack.

Băcanu says that ambulatory patients, in particular, face major problems getting access to cancer drugs that have to be administered intravenously. The reason, he says, is that the list was not discussed by

“For the first time, oncologists could vote freely for their representatives without undue influence”

professional organisations such as the Society of Medical Oncologists, and that the new regulations were proposed by hospital-based oncologists who dominate the Commission, and are blind to the needs of patients who are treated in the community.

This bias, he says, is also reflected in the disparity between the budget available for hospitalised patients and the outpatients, which he passionately argues must now be addressed as a priority issue. “All these new drugs are approved by the commission of the health insurance system, but the financial support for this plan is very poor and only around 5% of the patients on the waiting list can actually have these new drugs. This is a big sadness for the oncologists. We want to treat all the patients. By what criteria can we choose this 5% from the waiting list?”

The training and status of oncologists have proved less controversial. The Commission has made a strong recommendation that not every surgeon has the right to operate on cancer, says Băcanu. Surgeons will not be allowed to operate if they have no specialist training or if their institution is not recognised as competent to manage cancer patients, and in some cases, such as breast cancer surgery, they must have a minimum annual case load.

Another key concern has been reversing a decision taken last year to withdraw the status of medical oncology as a specialty. This would mean that cancer patients will in future be treated by doctors who are trained only in internal medicine, with only five months training in oncology, in contrast to the five years of training that used to be required. Romanian oncologists took the issue to court, and won a ruling in their favour. Though the Ministry promised to abide by the ruling, it has not said when it will do so.



Taken as a whole, things are certainly moving in an encouraging direction. Băcanu argues, however, that cancer patients will only feel the impact if politicians show political will and harness the power of the media to change public attitudes towards cancer. Above all, the issue of how Romania will finance an adequate healthcare system needs

to be tackled head on in the public arena. He wants the chance to present to a mass audience the dilemma faced by oncologists when they cannot do much except put patients on a waiting list. “It is necessary to explain to civic society that there is an urgent need to increase taxes to fund the health care system,” he says, adding that the discussion needs also to look at other ways of funding healthcare. He is encouraged by moves in the media itself to address some of these issues, citing a new TV channel called ‘Good Life’, which gives extensive coverage, including debates, to health and healthcare issues.

Farcas does not deny that adequate resourcing will be necessary to pull cancer treatment up to European standards. But she believes the first crucial step was to make the voice of patients heard. And it has been heard, loud and clear.

“I don’t want to defend the Ministry,” she says “but I observe that they have, for example, made huge progress in communication with the population, and with the patients they have a very open strategic platform already. Today I can phone the Ministry and ask questions such as when and how will you sort things out, and they give me names and answers.” Anyone who has spent as many years as she has trying to get information and responses from the shadowy figures who used to run the health show in Romania will understand just what a step forward this is.

“Politicians must show political will and harness the power of the media to change public attitudes”

Polish reporter wins ESO award for coverage of colonoscopy screening

Colonoscopy screening has the potential to save thousands of lives, but only if the public is prepared to go along with it. Polish journalist **Pawel Walewski** won the ESO Best Reporter Award 2007 for his article on the subject '*It's a shame to be ashamed*'. It was first published in *Polityka*, Poland's largest-circulation weekly, and is reprinted below.

Forget it: wholemeal bread, grains and their fibre will not protect anybody against colon cancer. The only way you can defend yourself against it is to launch an attack.

Colon cancer is one of the most common and dangerous neoplasms in Europe today. In 1993 just under 10,000 cases of the disease were recorded in Poland. Ten years later (the most recent data are from 2003), this had risen to 12,000. And the hopes expressed at the beginning of the 1990s that fibre could protect intestines against cancer did not come true.

"I don't deny its importance in regulating the functions of the digestive system, but there is no evidence that it prevents colon cancer," says Professor Eugeniusz Butruk, head of the Gastroenterology Clinic of the Medical Centre of Postgraduate Studies in Warsaw. "A diet based on brown bread, grains, fruit and vegetables continues to be beneficial for health, as is physical activity and maintaining the right body weight, but nobody has been able to find evidence supporting the thesis about its anti-cancer properties." However, we do stand a chance of winning the fight against this killer.

That colon cancer holds second place in the oncological ranking of numbers of cases and

deaths, after lung cancer in men and breast cancer in women, suggests that this neoplasm is not easily treatable. Paradoxically, this is not so. If you can start treatment at an early stage of cancer development, the proportion of patients cured amounts to 90%. So why does this disease, particularly in Poland, take such a tragic toll? The reason is that we don't look out for the symptoms and are unwilling to undergo examinations that can help detect it early.

Colon cancer grows slowly. It usually takes up to a dozen years or so for a small polyp appearing in the colon or rectum as a result of mutations of various genes to grow into a tumour. Polyps are frequently asymptomatic. In some cases they may bleed a little, which should actually make us pleased, because

then blood can be seen in the stool and the alarmed patient will look for the doctor's help more quickly. "However, most often nobody notices bleeding from polyps, which grow in the large intestine without causing any ailments," says Professor Jarosław Reguła, who heads the Endoscopy Laboratory of the above-mentioned Gastroenterology Clinic. "Our patients are finally alerted to their problem by anaemia, weight loss and changes in the rhythm of bowel movements."



It's your choice. Articles like this one, that present the facts about colon cancer – the importance of early detection, the effectiveness of colonoscopy screening, the debate about how to minimise the discomfort – give readers the chance to make informed decisions on whether or not they respond to that offer of screening

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These ailments, however, mean that the disease is already advanced, and in such cases the percentage of survival falls sharply, to 30–50%. “And please don't wait for any stomach pain before finally being persuaded to go to a doctor,” warns Professor Jarosław Reguła. “Stomach pain occurs in half the population, and it's most often caused by other factors. It's not a cancer-specific symptom!”

So how do you find out whether there is an insidious tumour developing in the intestine wall, or a polyp heralding such a tumour, when you are not oversensitive about your own health? To answer this question Professor Jarosław Reguła shows us a flexible cable, one metre and a half in length, with an endoscope and a digital camera, which is inserted into the patient's intestine through the anus. “It is used to perform colonoscopy, an examination to assess the appearance of the inner wall of the entire large intestine. That's how we can look for polyps, and if we encounter an early form of cancer or a precancerous change, we can immediately and effectively eliminate it without an operation.”

Colonoscopic examinations do not enjoy a good reputation anywhere in the world. They are certainly one of the most embarrassing and unpleasant examinations in contemporary medicine. Various methods are used in different countries to familiarise people with colonoscopy. In the US, for example, Katie Couric, who is a well-known presenter of a morning television programme and has recently become a



leading CBS newscaster, underwent this type of examination before the audience of a million viewers several years ago, believing it to be the best way of enabling Americans to get over their embarrassment.

Katie Couric knew only too well that colonoscopy could save the lives of thousands, because her husband had died from colon cancer and his ostentatious aversion to doctors. According to oncologist Professor Cezary Szczylik, every colonoscopy should be performed under anaesthesia: “I don't know anybody who would allow it to be performed again without an anaesthetic.” Professor Eugeniusz Butruk looks at it a little differently. “I've been doing colonoscopy without anaesthesia for 30 years. I am fully aware that it is unpleasant, but it doesn't have to be traumatic. Everything depends on good cooperation between the patient and the doctor, so the doctor can pick up even the smallest sign of anxiety and react appropriately.”

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However, if we are to expand the use of colonoscopy and encourage patients to undergo the examination, there should be an option of having it done under anaesthesia. International standards differ in this respect. For example, in the US and France nearly all examinations are performed under anaesthesia, but in Norway it is done without anaesthesia in most cases. In our national screening programme, which is set to cover an additional 35,000 people by the end of this year, the price of anaesthesia (PLN 100–150) will be taken into account for every third examination. The other 70% of those insured can pay for it out of their own pockets if, of course, they find it necessary. “I'm happy that that programme can be carried out at all,” says Professor Marek Nowacki, Director of the Oncology Centre. “There was not enough money for it in the past and the results so far are unique. We have published them in the *New England Journal of Medicine*, the world's most important medical journal.” The doctors from the Warsaw Oncology Centre have indeed proved and described that advanced precancerous changes in the large intestine occur nearly two times more often in men than women in analogous age groups. Professor Jarosław Reguła, the chief author of the article, adds, “It turns out that, as a result of polyp removal, the incidence of colon cancer is reduced by up to 90%. Therefore, colonoscopy is used not only to detect the disease, but it is also an effective method of preventing it.”

Who should have it done? Everyone who has turned 50 should undergo colonoscopy every 10 years. If someone in your family has had colon cancer or suffered from polyps, you should report for regular examinations every five years from the age of 40 (the website www.coi.waw.pl/jelito.htm presents more information on this topic together with addresses of about 80 facilities participating in the screening programme, to which people aged 50–65 are invited).

“It's a shame to be ashamed” – this is the slogan that Professor Eugeniusz Butruk would use to encourage patients to undergo colonoscopy. But is it not also a shame that Polish results of colon cancer treatment are among the worst in Europe? Only 25% of patients survive five years from the moment the disease is diagnosed (the rate is three times higher in the US). “It's not only patients at fault,” says Professor Adam Dziki, Head of the General and Colorectal Surgery Clinic of the Medical University in Łódź. “General practitioners are sometimes at fault because they don't take any interest in this part of the body; or the system in which people with cancer escape medical control should be blamed. If a facility deciding to treat cancer does not track its patients, it should not deal with oncology at all.”

According to Professor Cezary Szczylik, there is yet another reason for disastrous treatment results: limited access to new pharmaceuticals. The removal of cancer (often with a piece of the intestine) is certainly the gold standard in this therapy, but the more or less extensive operation should be followed by radiotherapy and chemotherapy.

“There are better and better pharmaceuticals, monoclonal antibodies which prolong patients' life, they are so fashionable in modern medicine,” says Professor Cezary Szczylik. He gives an example of bevacizumab, which precisely hits one of the proteins stimulating the development of blood vessels around the tumour. In metastatic tumours, cetuximab is effective as it targets the protein stimulating the proliferation of tumour cells and increases their death rate (apoptosis).

According to the World Health Organization, colon cancer will kill 655,000 people in the world this year. The only thing we can do is remember about regular examinations. The team of Professor Jarosław Reguła has recently received a reply from a patient who was personally invited to a colonoscopy: “Keep away from my butt!” The professor adds: “You can't examine anybody by force. We can only explain that we want to save life in this way.”