Social Cohesion Developments

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Health as a social right

Editorial

50 years of commitment to health

The 50th anniversary of the European Health Committee (CDSP) marks half a century of commitment to Europeans' health. This certainly warrants a special issue of the electronic newsletter "Social cohesion developments".

Health is of paramount importance as a key asset and component of human life, a human right and a factor for social cohesion and democratic stability, so it is hardly surprising that as early as 1954 the Council of Europe decided to focus on promoting and protecting health.

By including this area in its work programme, the Council explicitly recognised the importance of promoting and protecting health. This is one of the "ideals and principles which are the common heritage" of the Council of Europe member states and "facilitate their economic and social progress"[1].

In fifty years, enlargement in stages has brought the membership of the Organisation and the CDSP up from 15 states[2] to 45. But this expansion has not affected the initial matrix of the Council's work on health, all of it geared to ethics and human rights. The approach adopted places the individual patient at the core of all health policies, assigning him or her the role of a responsible citizen. This is the distinctive feature of the CDSP's work and that of other Council bodies active in this area. To underscore the strength of the whole Organisation's commitment, we have asked these bodies to take part in this special issue. We have also sought the involvement of civil society, especially patients' associations, which are essential partners for all forms of democratic governance.

The sequence of the articles demonstrates that the actual conception of health policies and practices is centred on fundamental freedoms and a concern for disadvantaged people. They are based on the principles underlying the dynamics of social cohesion: access to care, fairness, quality, safety, patients' rights, solidarity, non-discrimination and distributive justice.

In these terms Europe is a so-called "advanced" region, but it is by no means free from the intense growing pains of globalisation. Health policies are evolving in an increasingly complex setting, with demographic change and environmental damage as the greatest threats, which are supposed to be curbed by advances in research and technology. More covertly, financial pressure is increasingly weakening existing social protection and health care systems.

Closer monitoring of these developments is needed to preserve what has been achieved so far, since economic efficiency is best supported by social cohesion, one of whose mainstays is health policy. The idea is not to fuel discussion on this point, because a disintegrating social fabric obviously cannot guarantee development. The Council of Europe's purpose is rather to explore socially committed ways of sustaining health care systems geared to ethical principles and human rights. As the CDSP in fact recently suggested under the Netherlands chairmanship of the Council of Europe, the response to this challenge will have to be a new forward-looking strategy in terms of health-related activities in Europe.

The newsletter opens with two interviews outlining health issues in political terms. It then looks at the CDSP's background, the challenges facing it and the impact of its work on countries in transition, which form almost half its member states. This is followed by brief descriptions of the CDSP's main achievements, some of which, such as blood transfusion and organ transplantation, have gained it a worldwide reputation. This is also true of other sectors of the Council of Europe such as the Pharmacopoeia, the European Court of Human Rights, the Parliamentary Assembly, the Social Charter, the Pompidou Group and the public health sector, as well as the Biomedicine Convention and the Anti-Doping Convention.

This newsletter is not designed to be exhaustive but to offer the reader an introduction. It aims to pay tribute to the achievements and commitment of all those involved in and working for health policies in Europe. As an introduction, it may prompt the reader to seek further information. Please ask us for details if you so wish.

1) In Article 1 of the Statute of the Council of Europe.

2) One of these, Saarland, no longer exists.

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Content

Interview with Mrs Clémence Ross van Dorp
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Views on health as a fundamental social right.

Good health is high on everyone's list of priorities. Health is important, not only to the individual but to society as a whole. A healthy population is a prerequisite for social cohesion and democratic stability. We recognize a principle of "the social right to health care", which in policy terms means that the government must seek to reduce the differences in health between certain sections of the population, prevent illness, eradicate disease where possible, provide proper health protection, and ensure that affordable, high-quality healthcare services are available to all. However, the individual also bears a personal responsibility. He or she should adopt a healthy lifestyle, should not call upon healthcare services unnecessarily, and should not rely on the government where individual arrangements can be made.

Newsletter: What do you regard to be the main advances in European health and healthcare policy over the past fifty years?

The Council of Europe has been responsible for a number of important healthcare advances, in both policy and practice. For example, the 1953 flood disaster in the Netherlands prompted the Council of Europe to institute the current 'pan-European' blood bank system. It developed a 'gold standard' for blood and blood products (and more recently for human organs and tissues), whereby the patient is now assured of safe transfusions and transplants in all of the member states.

Another important move by the Council of Europe has been to place focus firmly on the patient, both as healthcare consumer and as a contributor to the decision-making processes. Today's technological advances in medicine seem to offer practically unlimited opportunities to repair any human ill, but each form of treatment creates its own chronically ill, and the demand for healthcare services is growing by the year. It is extremely important to keep the legal aspects in mind, as well as ethical standards and the responsibility of the individual. The Council has introduced a practical integrated approach to these considerations, which has made a substantial contribution to ensuring humane and effective care in all member states.

Universal access to high-quality healthcare provisions is also a European issue. Accordingly, the Council has done much to preclude any socio-economic divide, and to promote social cohesion both within and between the member states.

Newsletter: What are the challenges and risks that must now be anticipated?

First the risks. These are mainly the result of social changes and advances in medicine itself. A somewhat litigious culture is emerging, which has given rise to 'defensive medical practice'. This is not in the interests of patients, and creates unnecessary costs. Other risks which threaten effective healthcare are commercialisation and a lack of resources, particularly in terms of time and manpower. Although certain cutbacks are necessary, we must never lose sight of the human aspect.

The challenges relate to the changes that technological advances will inevitably bring about. How, for example, can we ensure that new predictive testing methods are used only in the best interests of the patient, rather than being dictated by the market? When the HIV pandemic first emerged, the Council of Europe introduced a very successful policy which ensures appropriate balance between individual interests and those of public health. Perhaps the Organisation would be equally successful with a new policy to address other infectious diseases.

The success of public health policy is closely linked to the degree of respect accorded to the individual. The Council of Europe could contribute by operating flexibly with a focus on content rather than structures, and by demonstrating that its activities are undertaken in line with the mandate and responsibilities of the Organisation. In fact, this is the thinking behind the Dutch proposal for a strategic approach to healthcare and related activities, put forward during our presidency of the Committee of Ministers.

Newsletter: What priorities should the European member states address in order to ensure universal access to healthcare services?

In my view, the first priority must be to ensure proper care for those whose options are restricted for whatever reason. Due attention must be devoted to the more vulnerable members of society, certainly in an overwhelmingly economically-oriented climate. Member states should also invest in the social climate. It should educate people that not every wish comes under the heading of a 'medical necessity'. The training for healthcare providers should include the need for professional restraint, and should stress the importance of respect for patient rights.

Newsletter: In the context of population ageing, how can the necessity of reforming social security systems be reconciled with the guarantee of quality health systems and universal access?

What is needed is a more equitable distribution of funding on the basis of actual need, both in scientific research and in the care and cure sector. We also need new social arrangements in which mutual help and support are seen as a "given", and more flexible structures in the healthcare system, enabling the elderly to live in their own familiar setting for as long as may be regarded responsible.

Interview with Mrs Taru Koivisto
Chairperson of the European Health Committee (CDSP)

Background presentation

Working as Senior Officer in the Finnish Ministry of Social Affairs and Health, on the Health Department in the Unit for Health Promotion. Main responsibility: the Finnish Public Health Programme, Health 2015, and its implementation.

Education: Master's Degree in Health Care Administration, Helsinki University

Representing Finland in the European Health Committee and in the Public Health Committee since 1998, in the bureau of the Health Committee since 2000 and Chair since June 2003.

Newsletter: What are the main areas in which the European Health Committee has influenced the European health agenda over the past 50 years?

The most important achievement of European Health Committee was to put health into a perspective of equity, ethics and human rights ever since its creation in 1954.

One of the most successful activities has been the elaboration and promotion of ethical and safety standards in the area blood transfusion and more recently in the field of organ and tissue transplantation. The European Health Committee has developed standards that now form the basis of national guidelines in all European countries, which have been translated into more than 20 languages.

Another area to be mentioned is the important contributions to equity in access to health care for the most vulnerable of our populations. Numerous recommendations have been adopted to ensure that the most disadvantaged of our societies receive the necessary treatment independent of their social status.

Newsletter: What should be its priority areas today?

Management, organisation and problems of health services in the 45 member states of the Council of Europe differ considerably. The challenge is to identify areas of common ground.

Patients' rights and citizen participation are one area of common interest ideal to be tackled at a pan-European level since there are no geographical particularities: all patients should have the same rights universally, in every country.

Work in the area of blood transfusion, organ and tissue transplantation should continue while addressing new challenges. For example, on the issue of organ trafficking the European Health Committee has just adopted a draft recommendation, which contains guidelines to member States with a view to minimising the risk of organ trafficking.

Another issue is to find ways how to combine forces, where possible, with other organisations such as the World Health Organisation and the European Union. Resources have to be used in the most optimal way.

In that context, reference should be made to a proposal made by the Netherlands during their Chairmanship of the Committee of Ministers, where they call for a more strategic approach to health and health related activities – inside the Council of Europe and in co-operation with other organisations. This document should form the basis of our future planning.

Newsletter: What role could the European Health Committee play to enhance citizens' health after EU enlargement?

Even after European Union enlargement, the Council of Europe has 20 more member states than the European Union. At the same time, European Union enlargement will affect our work. In the area of blood transfusion, organ and tissue transplantation, we have to ensure that our work will form an integral part of the European Union legislation process as regards safety standards. On issues related to health services and health care developments, where the European Union has no legal competence, the European Health Committee is the ideal platform to issue pan-European guidelines to avoid a two-speed Europe.

Newsletter: What does the Council of Europe need to do to help the European Health Committee to fulfil its role?

Health and health-related activities are fragmented and dispersed within the Council of Europe. Mechanisms have to be found to develop a more coherent approach thus enhancing visibility and to strengthen efficiency. The Netherlands proposal deals exactly with this issue and should show the Council of Europe the way for the future.

Health activities in the Council of Europe have always enjoyed very strong support from member countries – it's time that this support translates into the necessary financial and staff resources.

Interviewer: Cathie Burton

Challenges and development

Over the past fifty years there have been a lot of changes in public health. In the early years of the committee, which used to be called the European Committee for Public Health (CESP), many member states had no specific health ministry and the issues were covered by the ministry of the Interior, Family or Labour. At that time, economic factors were not the main determinants of health; a country with more hospital beds was regarded as having a higher standard of health care delivery.

According to its terms of reference, the CESP, which had around half of today's members, worked for greater unity between member states in health issues. Most of the initiatives of that time are of acute importance still today, for example health care for old people living at home or health education in schools.

The geopolitical changes in Europe around 1990 were of utmost importance for the work in the years to come: the Council of Europe became a bridge between different parts of Europe, the number of member states increased from year to year. The CDSP worked on specific programmes and numerous initiatives to intensify co-operation between the countries of central and eastern Europe to raise their standards in several health areas, for example regarding blood transfusion and blood safety. The Committee worked to ease accession of member states from central and eastern Europe to the European Union (EU), as we have just experienced.

The conferences of European Health Ministers of the Council of Europe were unique opportunities where the results of the endeavours of the CDSP became visible and received publicity. The first Conference of European Health Ministers of the Council of Europe was held in Madrid in 1981 and the subject was "Preventive medicine and education for health". The last Conference of European Health Ministers in June 2003 concluded with the Oslo Declaration on Health, Dignity and Human Rights.

Another factor has influenced the scope of activities of the CDSP: the increasing importance of the European Union in the health field. Article 129 of the Treaty of Maastricht and Article 152 of the Treaty of Amsterdam as well as recent judgements of the European Court of Justice have broadened the field of competence of the European Union considerably. As the membership is becoming more and more identical, co-operation between the three major actors in the health field in Europe – Council of Europe, EU and WHO – is ever more necessary. The terms of reference of the CDSP note that the committee should "cooperate very closely and coordinate with other international organisations working in the field of health, and particularly with WHO and the EU". The exchange of letters signed in June 2001 between the three actors has been a step in the right direction.

Through five decades the CDSP has looked at health issues from an ethical and human rights point of view and has contributed through its resolutions, recommendations and other conclusions to substantially shape the landscape of public health in Europe.

Helmut Voigtländer
Former Director of International Health Relations and EU Affairs, Federal Ministry for Health and Social Security, Germany

Health and social cohesion: the current challenges

The Council of Europe, with its unique human rights positioning, takes stock today of more than fifty years of work in the health field, guided by the European Health Committee (CDSP). However, in today's enlarged Europe of 45 member states, basic health indicators still show major differences. Greater unity between member states through health is still a great expectation for millions of Europeans. Entering the 21st century, the Council of Europe cannot fail to remain committed to health and offer its valuable potential to help facing the numerous health challenges embracing all European countries.

"The Council of Europe is the ideal platform for the creation of a Greater Europe of Health and Social Cohesion, capable of meeting the needs of the entire continent."

Ms de Boer-Buquicchio, Deputy Secretary General 7th Conference of European Health Ministers (Oslo, 12 June 2003)

Technological innovation, particularly in communication and medical science, is a dominant new feature of this century. Modern information technologies cutting through time and space help considerably to improve access, quality and effectiveness in health care. Health care is now a global issue.

This new century is also the age of the human genome. Applications of genetics are emerging and their potential is huge. Genetic screening and testing, cellular therapies, embryo-based research, human cloning are all promising tremendous potential improvements in the health field. However, this also calls for wise scientific and societal behaviour to establish limits to the implementation of the technically possible.

European populations are ageing. These demographic changes are having a considerable impact on health services and medical care. Elderly are becoming a growing group of paramount importance, their health needs, in terms of care and structures will be rising. As full members of our society, older generations deserve full respect of their fundamental human and social rights to avoid their marginalisation.

Transportation is swifter, boundaries are falling down. Individuals can circulate freely in most European countries. Economically better-off European countries become the destination for patients in need of care and for health professionals. Our societies are becoming increasingly multicultural.

Impacts of the dynamic changes described above will be considerable. Member states have the responsibility to organise flexible, adaptable health care systems combining quality, effectiveness and efficiency; ensuring fair access to preventive health care and high quality medical treatement; setting up minimum health standards as well as ethical and legal limits in the implementation of new health technologies.

The Council of Europe is the appropriate body for ensuring that there will be no new dividing lines in Europe, no further inequalities in access to health care. The current development of health indicators[1] may offer a frame of reference for devising health societies. At the same time, they could also help to identify areas where further studies are to be carried out. The work of the European Health Committee (CDSP) has always lied within this scope. Since its creation, its principles involved a strong commitment to ethical and human rights values as well as to achieve greater unity between member states in the field of health. The European Health Committee will continue to act in this dynamic.

1) These indicators are developed in the framework of the Methodological Guide to the development of social cohesion indicators to be published shortly by the Council of Europe.

Karl-Friedrich Bopp
Head of the Council of Europe Health Division

The "East Side Story"
CDSP recipes for health policies in transition countries.

Fifteen years ago the movement called "Solidarity" was the first to undermine the totalitarian system in Eastern Europe. It was a paradox of history that exactly social solidarity was the first victim of the transformation processes.

Not being a funding agency, the Council of Europe attempted to promote its traditional values in reply to the urgent needs of the new member states. "Money makes the world go round", but the Council's values showed the direction to go towards. Protecting the vulnerable was the first concern of countries in transition – and the set of policy guidelines were ready to use. Similarly, the well deserved reputation of the Council of Europe as a reference point in blood and organ safety, combining ethical rigor and technical excellences, were ready to become the basis for many national guidelines and policies.

The growing demands from countries in transition offered a rejuvenating therapy to the Council of Europe. It was a discovery that the Council of Europe could offer assistance not only in re-building democracy, the rule of law and human rights protection, but also in the domain of social and health policy. Increasingly, the new member states' needs influenced the work of the CDSP. The growing demand for assistance programs, limited by the capacity to supply, led to a number of pragmatic, needs-driven and solution-oriented activities (Lithuania, Bulgaria, Georgia). A good example is the development through two projects of a new human and patient rights culture in Russia: on human rights issues in the tuberculosis control policy and the project in Chelyabinsk, dealing with the human rights aspects of health promotion and preventive policies.

It had a symbolic value that the first post-communist era Ministerial Conference took place in Warsaw in 1996 and was devoted to the core question of "Patients Rights in the context of health reforms". The Ministers called for a new social deal on health, with the empowerment of individuals to look after their health and the participation of all the protagonists, based on values enshrined in the European Convention on Human Rights and the European Social Charter.

Health became a bridge to peace in a pioneering type of continuous assistance programmes: the South-East Europe Health Network, in the framework of the Social Cohesion Initiative of the Stability Pact, run jointly with the World Health Organization (WHO) has become a model of both regional cooperation and partnership between WHO and COE. It was supported by the Council of Europe Development Bank, the only financial institution with an explicitly social mandate, which was in fact one of the instruments by which the many dimensions of the Council of Europe's strategy were implemented.

Active participation of the new member states in the expert committees served to share the experience of the "health politics" in the making. Half of the experts of the Expert Committees come from the new member states. Many of the topics have been influenced by the needs of transition countries. The Council was the first to promote citizens voice in health care, to offer comprehensive strategies on quality improvement systems, on criteria for managing waiting lists and on a methodology for drawing up best practice guidelines. The latter become a model example of a European launch of a recommendation - during the international conference on "Information and quality in healthcare" (2003, Krakow) it has been thoroughly discussed at the satellite workshop, with 50 participants from 15 countries.

An effort is being made to link policy recommendations with assistance activities by organizing the final meetings of an expert committee in a partner country, attached to a local or regional workshop on the subject.

The reforms in the transition countries led to the transformation of their health system, converging with those existing in the rest of Europe. Thus a common European health agenda emerges. This is reflected in the current work programme of the CDSP which responds to common health challenges: patients' safety; mobility of health professionals; health care in a multicultural society.

It was significant that health has been included as one of the priority issues during the chairmanships of the Committee of Ministers by the new member states, including the conference on "Health Reforms in Europe: from Policy to Practice" (Vilnius, 2002).

The unique social and economic global experiment of transition from totalitarian to democratic systems has not been properly documented by any of the international actors. The similar deficit of monitoring and evaluation at the Council has been recognised and is being addressed.

The Council's moral authority in the fields of human rights and democracy continues to accompany the states emerging from Communist rule in the transition process and created a platform for mutual exchange of experience between member states. It complemented the "invisible hand" of market reforms with the "visible handshake" of the social cohesion approach. In the face of the enlargement of the European Union the Council's role remains to prevent any new "iron walls" made of new social and health divides.

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Vulnerable but valuable – the Council of Europe approach to healing social wounds.

"If the free society cannot help the many who are poor, it cannot save the few who are rich"

President J. F. Kennedy

Why care about vulnerable? Because it is at the heart of the vocation of health care – sickness in itself is a cause of vulnerability. Vulnerability is a combination of risk (a chance to get harmed) and a hazard (a situation which may cause harm). Each society has its own pattern of vulnerability: elderly, minorities, the poor, people in institutions, the socially excluded. Vulnerability exists even in more affluent societies and leads to the gradient of social injustice. The Latin word "*vulner*" means a wound. Vulnerability is a wound on the body of a society, a social disease which needs a social cure. The Council of Europe Social Cohesion Strategy attempts to offer an appropriate remedy. Equity and social justice cannot be achieved without addressing the needs of the vulnerable and the accompanying loss of human capital.

Therefore, in a series of studies and recommendations, the scope and the root causes of the vulnerability, effective solutions and models of good practice have been addressed. The focus has been on building a framework for the vulnerability reduction strategies. A dynamic notion of vulnerability was developed – a realisation, that "vulnerability could hit anybody at any time" (Ministerial Conference on "Health, Dignity and Human Rights" - Oslo, 2003).

The initial impulse came from the "Human Dignity and Social Exclusion Project" (1995-1998), which established three dimensions of social exclusion: a weak relationship to the State, to the labour market and to family and society. Vulnerability affects a chance for a life commensurate with human dignity.

A series of policy guidelines on health care for persons in vulnerable situation followed (Rec(1997)4 on single-parent families, R(1998)7 on health care in prison and R(1998)11 on the chronically ill), crowned with the Committee of Ministers' Recommendation Rec(2001)12 on "the adaptation of health care services to the demand for health care and health care services of people in marginal situations".

While preparing the recommendations, the committees of experts reviewed the current policies on vulnerability and found many deficiencies: empty words, poor conceptual frameworks, an information deficit, lack of a multisectoral systematic approach, democratic deficiencies, lack of preventive policies.

In reply, the Council of Europe recommendations advise:

- to take care of the vulnerable not as a matter of expediency or solely for purposes of social cohesion but because each and every citizen has the equal right to receive care according to his or her needs;
- to develop of a coherent and comprehensive vulnerability reduction framework, to prevent insecure conditions and therefore limit the risks of falling into vulnerable situations;
- to do away with the static categorisation of populations and place emphasis on prevention in the widest sense; health policies should be conceived not only with vulnerable groups in mind but conscious that the whole population is potentially vulnerable;
- to avoid fragmentation into separate health "systems" for separate groups;

  to prevent vulnerability cannot be the sole responsibility of the Health Ministers – a multi-sectoral approach is required: "fight the vulnerability, not the vulnerable";
- to avoid stigmatisation and a dependency culture;
- to develop a democratic partnership – "talking with them, not to them".

In a quickly evolving European society, new causes of vulnerability will emerge and call for new approaches. The recommendation on palliative care, the draft recommendation on "Patients and the internet" and the current work on health care in a multicultural society and on management of patient safety - all address these new sources of vulnerability.

Health issues at the Parliamentary Assembly

The right to protection of health is part of the Council of Europe *acquis*. The Parliamentary Assembly, a political body of the Council of Europe, strongly supports widening the scope of articles 11 and 13 of the European Social Charter (revised), and continually promotes the right to protection of health in the member states.

In September 2003, the Assembly adopted Recommendation 1626(2003) on the reform of healthcare systems in Europe. Mr Ovidiu Brinzan, rapporteur on behalf of the Social, Health and Family Affairs Committee of the Parliamentary Assembly and now Minister of Health in Romania, insisted that the reform processes in member states should seek to reconcile the often contradictory terms of maximising quality, efficiency and equality of access to healthcare as well as guaranteeing the viability of the system, against a background of limited government resources and rapid demographic and technological change.

The Assembly holds that in line with the objective of greater social cohesion and solidarity, the main criterion for judging the success of health system reforms should be effective access to healthcare for all without discrimination, which is a basic human right.

It recommended placing greater emphasis on prevention and primary care, in order to counter the financial pressure involved in providing universal health coverage and the increasing costs associated with secondary care. The Assembly also called on the member states to strengthen respect for patients' rights.

Very recently, the Assembly adopted Recommendation 1661(2004) on the future of social security in Europe, as a response to pressures of global economy to deregulate standards of social protection. Mr Claude Evin, rapporteur and former Minister of Health in France, stressed that "social security has a cost, but it can cost still more economically, socially and politically

to be without social security". The Parliamentary Assembly recommended to the Committee of Ministers to include the question of social security and the fight against poverty on the agenda of the third Summit of Head of States and governments of the Council of Europe and to promote the inclusion of five principles of Recommendation No. R(2000)3 of the Committee of Ministers into the European Convention on Human Rights system.

With regard to health, the Social, Health and Family Affairs Committee of the Parliamentary Assembly is currently preparing reports on European strategy for the promotion of sexual and reproductive health and on strengthening the response to mental health needs in Europe.

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The Right to Health as a Human Right in Europe

Health is a key issue for every human being and protecting health is generally recognised as a fundamental human right. Providing guarantees to protect health is, however, something that states find difficult to fully ensure in practice. In principle, two legal approaches are available: provisions for protection of health in general and for care of sick persons.

General health protection is indirect, covering: the living environment, in areas such as safeguarding against pollution, maintaining safe housing standards and keeping checks on the working environment; the promotion of healthy lifestyles, for example, campaigns against alcohol and drug addiction; and the prevention of ill-health through, for example, vaccination programmes, screenings, measures taken to reduce accidents, etc. And then concerning healthcare provision for sick persons, ways must be found to overcome

Two activities may be considered as a follow-up:

– a "survival handbook for the vulnerable";
– a study on usefulness of recently developed "social cohesion indicators" to guide policy on vulnerability.

In conclusion, measures adopted to improve access for the vulnerable serve also the general population. That is why societies should claim "NO POOR MEDICINE FOR POOR PEOPLE". Caring for the weak shows the strength of the society - health of the vulnerable is the best indicator of the efficiency of health and social policies. The priority given to the fate of the vulnerable proves where the Council of Europe added value lies; to add the values of human rights, ethics and social cohesion.

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From declarations to deeds: the changing role of citizens and patients

There are two types of rights: citizens' social right *to* health care – to become a patient (as reflected in the European Social Charter) and patients' rights *in* health care – as a part of individual human rights (partially covered by the Oviedo Convention). In recent waves of health reforms, the role of patients has been one of the last to change.

The Council of Europe made a first attempt to issue a recommendation on the obligation of doctors *vis-à-vis* patients already in 1985. It was never adopted, but many principles therein could be found in the landmark WHO "Declaration on the promotion of patients' rights in Europe (Amsterdam 1994)". The historical step has been made – the language of doctors' obligations were turned into the language of patients' rights.

There is no Council of Europe recommendation on patients' rights as such, but they have been a leading thread in all recommendations on vulnerable populations and in many others which promote patients' voices in developing quality criteria, clinical practice guidelines and management of waiting lists.

Most people most of the time are healthy. The "healthy" citizens' role is to pay taxes or insurance contributions for the care they will consume when ill. So a natural conflict of interest develops: to minimize costs as a citizen, to maximize consumption as a patient.

There is a challenge to balance rights with democratic responsibility. The rights approach puts emphasis on a patient's choice as a "sovereign consumer" and their freedom of choice in the service market; the democratic participation approach empowers citizens' voices as responsible partners in shaping the health care system.

The Council of Europe has introduced the agendas of patients' rights and citizens' participation in health matters as a feature of a "health democracy". The Rec(2000)5 on the development of structures for citizen and patient participation in the decision-making process affecting health care makes this point clearly :"patient empowerment and citizen participation can be achieved only if basic patients' rights are implemented and that, in its turn, patient participation is a tool for the full implementation of these rights in daily practice".

The Recommendation recognizes that citizens' involvement leads to improvement of health systems through citizen empowerment and proposes methods to involve citizens and patients in all aspects and at all levels of health care systems: from information, consultation, partnership to full empowerment. It enlarges the individual principle of "informed consent" to the "negotiated co-decision". The draft recommendation on "Patient and Internet" offers additional tools to strengthen the health competence of citizens.

The time has come to consolidate the *acquis*. There is a European consensus on principles, there is a body of standards and experience, but there is no proper evaluation of developments and there is a serious implementation deficit. We need a new health "glasnost", which needs knowledge-empowered patients and a new "perestroika", which needs new instruments.

ill-health through medical research, diagnoses, treatment and rehabilitation.

The legal method for health protection is to set up specific standards, responsibilities and control mechanisms to guarantee a healthy environment and to enable public authorities to carry out any necessary interventions. Organising the provision of healthcare must include regulating the human, financial, technological and medical resources as well as legislating responsibilities per sector. The concrete supply of services, i.e. research, treatment and rehabilitation of patients is, however, not based on legal rules or assessments but on professional ethics, knowledge and skills of all health personnel.

The two key European legal human rights instruments, the European Convention of Human Rights (ECHR) and the European Social Charter (ESC), include provisions on the right to health.

Articles 2 and 3 of the ECHR provide protection for human life and prohibit degrading treatment, which might be understood to cover the necessary care for every individual person, at least in emergency cases. Moreover protection for adequate legal remedies is provided (Art.13). General health protection is provided under Article 11 of the ESC, regulating: health protection (para. 1), health promotion (para. 2), and prevention of ill-health (para. 3). Article 3 includes more detailed rules governing protection of health at work. The European Committee of Social Rights, ESC supervisory body, has developed the case law on Article 11§1 to include also the requirement of comprehensiveness and adequacy of the healthcare system and services available and, more recently, also general principles on waiting times for access to these services.

The ESC also includes a provision of medical insurance benefits (Art.12§1), which covers key rules for the financing of health services for those insured. Another provision regulates the finances for the services of uninsured persons (Art. 13). So, in principle the whole population should be covered

The time has come for concerted European action: to perform a comparative evaluation of the progress made; to develop a framework of "patients rights" impact assessment of other policies; to balance rights and responsibilities, to address the mobility of rights along with the increased mobility of patients; to avoid the pitfalls of predictive medicine and the danger of creating "genetically excluded" and possibly to expand existing binding instruments to include patients' rights and citizens' empowerment issues.

There will be no Eurocitizen without a Europatient. Adjusting the health systems to patients and not *vice-versa* is the right way from declarations to deeds.

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European Network of Health-Promoting Schools (ENHPS)

"Every child and young person in Europe has the right, and should have the opportunity, to be educated in a health-promoting school"

A health-promoting school is where all members of the school community work together to provide pupils with integrated and positive experiences and structures which promote and protect their health. This includes both the formal and informal curriculum in health, the creation of a safe and healthy school environment, the provision of appropriate health services and the involvement of the family and wider community in efforts to promote health.

The European Network of Health-Promoting Schools (ENHPS) is born from this spirit! In 1991, the Council of Europe, the European Commission and the World Health Organization (WHO) established the European Network of Health-Promoting Schools (ENHPS). The Network spread with enthusiasm. Today, 42 countries out of 45 member states of the Council of Europe are participating in the creation and running of school networks thus expanding the diffusion of health promotion to young people. Countries wishing to join the ENHPS need to express their commitment to the concept of the health-promoting school and support the principle of cooperation between education and health authorities at the highest level.

The ENHPS holistic approach to health promotion not only enables the introduction of fundamental changes to school approaches to education but, thanks to it, many schools traditionally hierarchical institutions with a top-down system of management are moving to a more open and participatory management style, in which staff and pupils have real opportunities to affect decision-making and bring changes. This generates a greater degree of democracy in the classroom which in turn contributes to building healthy and responsible young European citizens.

In an ever-faster moving environment, the challenge is constant. Our young generations are vulnerable in a world where social exclusion, poverty, obesity or drugs are only a few of the dangers waiting for them around the street corner.

The ENHPS is constantly addressing these issues and regularly considering the most appropriate methods for managing the complexities of these changes within health-promoting schools to ensure that it effectively fulfils its role as an agent for change. The ENHPS is an invaluable tool. It is a small investment for Europe with great returns measurable on several generations of young Europeans. It should remain a strong commitment of cooperation between the Council of Europe, the European Commission and WHO and should be allocated the resources necessary to continue its development.

Healthy and well-educated children and young people hold the key to the future of a peaceful and democratic Europe. Consequently, it is a fundamental right for them to be provided with the opportunities to realize the potential to become healthy, educated adults who possess the energy, skills and sense of responsibility so essential to their well-being in the modern world. The ENHPS has made some remarkable achievements and will capitalize on the further potential and technical expertise now evident in Europe, to meet the health promotion challenges of the 21st century.

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Meeting Challenges in the Area of Blood Transfusion

Work carried out in the area of blood transfusion has made the Council of Europe a leading European and world-wide organisation in this field. It builds on the promotion of the following principles: non-commercialisation of substances of human origin, voluntary, non-remunerated blood donation, self-sufficiency, quality and safety of blood and blood products and the protection of donors and recipients. These principles are implemented by studying the ethical, legal and organisational aspects of blood transfusion in order to ensure quality, increase availability, avoid wastage, and promote optimal use of blood, as well as to analyse the impact of new scientific developments.

Over the last five decades this work has resulted in numerous publications and recommendations which contributed to the promotion of the ethical principles and improved the safety and quality of blood and blood products. The most important recommendations have covered: the protection of the health of donors and recipients; the responsibilities of health authorities in the field of blood transfusion; the preparation, use and quality assurance of blood components; pathogen inactivation; the hospital's and clinician's role in the optimal use of blood; the prevention of the possible transmission of variant Creutzfeldt-Jakob Disease by blood transfusion; and the autologous cord blood banks.

The *Guide to the preparation, use and quality assurance of blood components* has become a "golden standard" for blood safety in Europe and beyond: it has been translated into more then 20 languages. It is up-dated annually with the 10th edition currently in force. In Australia it was mandated as part of national legislation. More recently, it became the basis for the technical requirements to be set under European Union Directive 2002/98/EC.

Providing practical assistance to the member states became a priority area in recent years. For example, special task force missions and training seminars have helped to improve and re-structure national blood transfusion services in Romania, Croatia, Moldova, Cyprus and many other countries.

As a contribution to the First World Blood Donor Day organised on 14 June 2004, a blood collection is being organised at the Council of Europe together with a seminar with a view to creating wider awareness of the importance of voluntary, non-remunerated blood donation.

Future challenges include following closely the development and use of new technology intended to improve blood safety and blood transfusion services in Europe as well as to give further guidance to clinicians in the optimal clinical use of blood.

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Addressing organ transplantation issues

Work in the area of organ transplantation was a practical follow-up of the 3rd Conference of European Health Ministers held 1987 in Paris. Since then, with the increased importance of organ transplantation as a life-saving operation, the Council of Europe has gained a world-wide reputation in this area.

While concentrating on ethical and organisational aspects, the Council of Europe has adopted numerous documents in this field. For example, the Recommendation on the management of organ transplant waiting lists and waiting times; the Recommendation on organ donor registers; a consensus document on meeting the organ shortage.

Despite all measures taken to raise awareness about organ donation, the main issue remains the organ shortage: no country has enough organs to cover its needs, and in some countries up to 15-30 % of patients die while waiting for certain organs. The lack of organs has led to patients becoming desperate in the search for organs: increasingly they are prepared to travel, to pay, or undergo illegal operations in order to obtain an organ. On 19 May 2004, the Council of Europe adopted the Recommendation on organ trafficking. It gives guidance to member states to put the proper organisational, legal and criminal system in place to minimize the risk of organ trafficking. The Recommendation reinforces the Protocol on Transplantation, which explicitly requires that organ and tissue trafficking shall be prohibited.

The second edition of the *Guide to safety and quality assurance for organs, tissues and cells* will be published in autumn 2004: the purpose of this document is to provide guidance for all those involved in the transplantation of organs, tissues and cells. As the European Union Directive on Tissues and Cells (2004/23/EC) was recently adopted, the European Commission will build on the guide on safety and quality assurance for tissues and cells when establishing technical standards under the Directive.

Assistance to member states to implement the Recommendations adopted gains in importance.

by the health care system. Further provisions regarding the right to health care, (equal access to services, good practice standards, patient rights) are still pending.

Societal changes, biological, medical and technical developments as well as economic, have all influenced the framework conditions of healthcare. These changes also affect the operative options of healthcare personnel, which in turn increase the need for improved healthcare regulations in the states and internationally. The European Health Committee (CDSP) is currently discussing a possible revision/up-date of the health content of the European Social Charter.

Dr. Matti Mikkola,
Professor of Labour Law at the University of Helsinki, Member and previous Chair of the European Committee of Social Rights

Biomedical research

The Steering Committee on Bioethics (CDBI) has responded to the bioethical challenges, both new and old, posed in the Convention on Human Rights and Biomedicine and its Additional Protocols. The Convention, opened for signature on 4 April 1997 in Oviedo (Spain) and now signed by 31 countries[1], is in force in the seventeen member states that have ratified it[2]. Its main principles are free and informed consent to any biomedical intervention, the primacy of the human being over the sole interest of science and society, and the protection of persons not able to consent. The Convention's principles are applicable to fields such as medical practice (including organ transplantation), biomedical research and questions related to human genetics.

The Convention focuses on the human rights aspect of biomedical research, unlike other legal instruments in this field, which may primarily focus on the economic, and public health aspects, of making new medicines available more quickly. The Council has extended its contribution in this domain by a draft Additional Protocol on Biomedical Research. In addition, the CDBI is preparing an instrument on Research on Stored Human Biological Materials.

The Convention's requirement for multidisciplinary review of the ethical acceptability of biomedical research projects has been emphasised in the Council of Europe cooperation programme (DEBRA) implemented in 1997-2004 in central and eastern Europe.

Biomedical research implicates fundamental rights and values, including scientific freedom, which has helped to, and promises to, produce scientific progress that can translate into cures for diseases and improved healthcare. However, such research must find a balance between scientific progress, which benefits many individuals, and protecting the specific individuals enrolled in biomedical research projects. The interests of such persons must always come before the sole interests of science or society. Hence, there cannot be total freedom of research to the detriment of other fundamental rights and values, just as the interest of society or science must be considered in a culture based on solidarity.

Specific bioethical challenges in biomedical research include issues related to ethical review of research projects, research intended to make progress on childhood diseases or senile dementia, research in emergency situations, multi-centre research being undertaken in several countries, and the linking of various data bases and tissue collections in new biobanks.

The CDBI's activities continue both in developing norms on specific aspects of this domain and in ensuring the application of existing norms.

1) As of 01/05/2004: Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Greece, Hungary, Iceland, Italy, Latvia, Lithuania, Luxembourg, Moldova, Netherlands, Norway, Poland, Portugal, Romania, San Marino, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, The Former Yugoslav Republic of Macedonia, Turkey, and Ukraine.

2) As of 01/05/2004: Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Georgia, Greece, Hungary, Lithuania, Moldova, Portugal, Romania, San Marino, Slovak Republic, Slovenia and Spain.

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Training seminars on improving transplantation systems were recently held in Latvia (with the participation of all three Baltic states), and Ukraine (with the participation of central and eastern European states); a task force mission was carried out in Hungary to advise on re-structuring its transplantation system.

To promote the ethical principles in the field of organ transplantation and to raise awareness among the general population about organ donation, the Council of Europe initiated the annual European Day of Organ Donation and Transplantation: the 6th Day will be held on 18 September 2004 in Athens.

Challenges remain. The Council of Europe will continue to update its *Guide on safety and quality assurance for organs, tissues and cells*. It will also carry on its work in the fields of organ shortage and organ trafficking and try to find new ways of developing living donation, xenotransplantation, international co-operation, training and education of professionals as well as raising awareness among European population.

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Xenotransplantation

Although the number of organ and tissue transplantations is always increasing, the needs still exceed may times the supply. Against this background, alternative solutions are being studied. These include xenotransplantation, i.e. transplanting animals' organs, tissues or cells into human beings either as a bridging device in patients awaiting human transplantation or as a definitive measure. These areas of research raise enthusiasm and hope for those waiting for an organ. However, it gives rise to certain concerns amongst experts and the general public.

As a response to these concerns, on 19 June 2003 the Committee of Ministers adopted Recommendation Rec(2003)10 on xenotransplantation. The Recommendation specifies that no xenotransplantation should be carried out in a member state that does not have a framework in place to regulate such a procedure. Xenotransplantation should only be carried out if no other therapeutic approach is available and if it has the potential to produce a clear benefit for the patient.

Patients participating in xenotransplantation programmes should be adequately informed of the possible constraints which may arise. However, in contrast with most other therapeutic procedures, xenotransplantation also has direct consequences on the lifestyle of the patient's close contacts. These include long-term medical monitoring, the importance of taking precautions with respect to sexual activity and even the possibility of isolation which may become necessary in the event of a contagious or previously unknown illness occurring. Once this information is given to the patients, their documented, express, specific, free and informed consent must be sought.

With respect to animal welfare the Recommendation underlines that all procedures relating to animals used in xenotransplantation should comply with the latest provisions of the Council of Europe and the European Union on the matter. These issues relating to animal welfare are all the more relevant since only animals bred specifically for this purpose should be used in order to minimize the risks of transmission of diseases from source animals.

To continue to maximize the safety aspects of xenotransplantation it is acknowledged that member states should cooperate through international surveillance procedures and agreements and should give immediate notification of any risks relating to public health that may arise.

Recommendation Rec(2003)10 on xenotransplantation is a unique ground-breaking international text in this field. It provides an important legal framework between European States in a fast-moving area where there are too few legal documents.

Xenotransplantation raises fundamental questions. This Recommendation invites member States to take steps to ensure that the important issues raised are the subject of appropriate public debates and consultations. These societal discussions with the public will then support the process whereby decisions are taken in a democratic context in the light of the relevant medical, psychological, social, economic ethical and legal implications.

In this field, like in many other health areas, once again, the Council of Europe shows its avant-garde position. This in turn triggers member States to take a stand for increased citizens' participation, hence ensuring that the remit of the Council of Europe - which seeks to promote the unity of the citizens of Europe and to respect democracy and human rights - continues to be realised.

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Preventing disabilities linked to chronic diseases

There are fears that chronic diseases will become the main cause of disability in the near future. The Council of Europe is therefore drafting a report on the prevention of disabilities linked to this type of illness, which it is hoped will be published in late 2004.

Although measures for combating chronic diseases (primary prevention) and the impairments they may cause (secondary prevention) are indispensable in preventing disabilities, chronic diseases are very special and require equally special measures to prevent the related disabilities (tertiary prevention).

The report recommends that impairments should be detected, diagnosed and treated at an early stage. Once an impairment has been diagnosed, the persons concerned and their families often do not know where to turn and are unable to obtain any precise information on the specific nature of the chronic disease or its symptoms and consequences. More information must therefore be made more readily accessible, for instance by training health staff. Appropriate psychological support for individual patients and their friends and families is also becoming an increasingly important aspect of rehabilitation programmes.

The full social integration and personal fulfilment of people with disabilities - which is the aim of the Council of Europe's policy for people with disabilities - also means that people suffering from chronic diseases must be integrated in education and at work.

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Integration of people with disabilities

Human dignity, full citizenship, independent living and active participation in the life of the community form the heart of the Council of Europe's activities for the integration of people with disabilities. The overall objective is to promote social cohesion in Europe by reconciling the principles of equal rights for all individuals and the concept of special needs.

See the 2003 Special issue of the Newsletter which was dedicated to the theme of «Integration of people with disabilities» on the occasion of the European Year of People with disabilities.

Visit also the Website: http://www.coe.int/T/E/Social_Cohesion/soc-sp/Integration/

The Partial Agreement in the social and public health field was concluded in 1959.

The areas of activity of the Partial Agreement in the social and public health field include two sectors:

- Protection of public health (CD-P-SP);
- Rehabilitation and integration of people with disabilities (CD-P-RR).

The activities are entrusted to committees of experts, which are responsible to a steering committee for each area.

At present, the Partial Agreement has 18 member states:

Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, Ireland, Italy, Luxembourg, The Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, United Kingdom of Great Britain and Northern Ireland.

Raising health protection and food safety

Within the Partial Agreement, the overall aim of the public health field activities is to raise the level of health protection of consumers and food safety in its widest sense.

The work is carried out by expert committees which have a conceptual and prospective approach and elaborate resolutions, guidelines and other technical documents with a view to evaluating potential risks and to proposing appropriate and adequate measures to assure effective consumer protection. The committees are at the forefront and also catalysts at European level in public health protection of the consumer.

In the field of nutrition, food safety and consumer health, the following concepts have been developed : guidelines concerning scientific substantiation of health-related claims for functional foods; action plans concerning nutritional care in hospitals; strategies for healthy eating at school; recommendations concerning dioxins and heavy metals in foodstuffs. The promotion of healthy eating, diseases linked to nutrition, such as overweight, obesity and type-2 diabetes are considered essential for the future work programme.

A source of contamination of food may be due to materials coming into contact with food and the packaging of the product since certain chemical substances in its composition may migrate into food (these substances are generally known as unintentional additives): A systematic approach has been applied in order to cover the different food contact material groups and to set the necessary measures in order to assure safety of use of these materials for the consumer. Resolutions and technical documents are now available for the main food contact material groups such as: colourants, aids to polymerisation, ion exchange resins, silicones, coatings, paper; metals and alloys, rubber, cork stoppers.

Regarding food contact materials, the Council of Europe has been a pioneer on the toxicological evaluation and elaboration of specific measures for flavouring substances. The 'Blue Book' on flavouring substances which classifies after their toxicological evaluation more than 1000 chemically defined flavouring substances may be considered as the main reference in this field in Europe. At present the work is orientated towards the toxicological evaluation of 700 natural sources of flavourings.

The publication of cosmetic products and their ingredients, may also be considered as a European standard and is a reference in the field of cosmetics. Further important standards on cosmetics have been studied and published: Guidelines for good manufacturing practice of cosmetic products; toxicological evaluations of plants and plant extracts used as cosmetic ingredients; resolution on tattoos and permanent make-up. Work on cosmetovigilance as a response to the Europe-wide increase of allergies, the increase of skin cancers and the effectiveness of UV sunscreen filters are important issues for the future.

Pharmaceutical products and medicines subject to prescription are increasingly important to the well-being of the consumer. Ensuring the safety and effectiveness of medicines and their appropriate use in society are of critical importance. Based on these principles the following topics have been dealt with: classification of medicines which are obtainable only on prescription; rational use of medicines; the role of the pharmacist in the framework of health security. Current and future priorities are counterfeit medicines; medication safety and the prevention of medication errors, legal classification of medicines.

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Changing illicit drugs consumption patterns and care of users

The Pompidou Group - a Council of Europe inter-governmental body committed to fighting drug misuse and drug trafficking - has three main missions concerning new trends in drug consumption: promoting information exchange, stimulating innovative processes and adopting good practice measures for the care of drug users.

The problems associated with new and changing drug consumption patterns, including the effects and impact of occasional and frequent consumption, must be addressed with a view to proposing measures to minimise the negative consequences for the individual and for public health and improving the quality and efficacy of care.

The Pompidou Group experts define "new drugs" as currently changing and emerging drugs and / or patterns of consumption, including poly-drug use; "new drug" users are people who use these products on an occasional or regular basis; finally, "care" is the response of the social and health systems to the needs and requests for treatment, information, secondary prevention and other risk reduction measures.

Trends and changes in the drug "market" are monitored by a close co-operation between the different government departments (police, customs and health) that countries have set up as early warning systems. The issue of research (epidemiological, pharmacological, neurological and especially therapeutic) plays a main role here.

Two surveys, one on current policies and practices for responding to new and emerging drugs and to new patterns of consumption, the other on national data about ecstasy, cocaine and amphetamines, were launched in an attempt to determine the scale of the problem in Europe. Their most pertinent findings are:

- cannabis remains the most frequently used drug but traditional drugs like alcohol, heroin and other opiates, LSD and so-called "natural" drugs (like hallucinogenic mushrooms) continue to occupy an important place in the new consumption patterns;
- the consumption of synthetic substances (ecstasy,amphetamines) and cocaine seems to concern festive users first and foremost and, to a lesser extent, drug addicts or regular users;
- the new drugs that raise the greatest problems of consumption are ketamine, GHB, synthetic drugs like benzylpiperazine, 2-CB or PCP, as well as solvents and gases (nitrous oxide, butane);
- pharmaceutical substances such as buprenorphine, methadone and codeine are increasingly being sold illegally;
- the number of patients receiving treatment for drug abuse is increasing world-wide and the problem of poly-drug use combining new and traditional drugs is also on the rise.

In general, countries are identifying the same substances and consumption patterns and it would appear that the problems caused by these new substances are increasing and likely to become more visible in the longer term. Recommendations which could be helpful to member States making decisions regarding these problems are currently being examined.

Most countries report that they are actively engaged in dispensing care to users of emerging drugs (information, prevention, risk reduction, treatment centres). Some examples of the interventions currently on offer include:

- the consumption of these drugs is discussed openly in the media (press and television) by politicians and professionals who work with drug abusers.
- a large number of countries suggest out-patient treatment for users of emerging drugs, combined with psychotherapy. This often needs to be coupled with pharmacotherapy. Psycho-social assistance is also proposed so that users have access to the most appropriate treatment all round.

A certain consensus exists to the effect that most cases do not really require the introduction of a new treatment system but merely the development of the various existing approaches.

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The Pompidou Group is composed of 34 member states. Since 1991 technical co-operation has been extended to countries of central and eastern Europe which are not members of the Pompidou Group. Furthermore, non - European countries, like Canada and USA, have also been invited to activities of the Group.

The Pompidou Group has three pillars of political commitment:

- Providing a liaison role for all the countries of Greater Europe through practical pan-European co-operation;
- Bringing together research and practice at the implementation level;
- Developing ethics and human rights dimensions in drug policies.

Europe's contribution to your medicines

The European Pharmacopoeia will be celebrating its 40th anniversary in June 2004. In July 1964, eight member states of the Council of Europe decided to work together to elaborate common quality standards for medicines. The International Convention on the Elaboration of a European Pharmacopoeia is the legal framework which applies to 31 European member states, and the European Union is an institutional member.

The aim of the Pharmacopoeia is to guarantee a high level of quality of medicines for all patients in Europe; it facilitates the free movement of medicines in Europe and provides a framework of reference to ensure the same level of quality control of medicines on the market. The member states have accomplished this by pooling their expertise and resources under the aegis of the Council of Europe in order to enable access to quality medicines for all Europeans. The European Pharmacopoeia is an essential means of protecting public health and fighting against counterfeit medicines.

Since 1965 the European body of regulations has grown considerably so that all aspects are now covered: production, clinical trials, marketing, pharmacovigilance, advertising and patient information. Today, the European Pharmacopoeia is still at the heart of the European regulatory system since European Union directives make compliance with its quality requirements mandatory for the marketing of medicines for human and veterinary use. Furthermore, to reinforce the collaboration and synergy between the European Pharmacopoeia and the European Union, the European Union became a full member of the European Pharmacopoeia Commission in 1994 and since then participates directly in its work.

European Pharmacopoeia requirements concern all medicines: innovatory products as well as generics, herbal medicines, homoeopathic medicines, or the latest generation of medicines produced using biotechnology (cells are used as 'factories' for the production of medicines such as antibiotics) or genetic engineering (genes can be inserted into cell nuclei to correct genetic defects in human patients or the medicine is produced directly from the gene, e.g. human growth hormone or insulin).

In 2003 new working parties were set up to elaborate quality standards in the area of gene therapy or to adapt to new types of production using modern microbiological methods. This common reference work now describes quality standards for 1500 substances used in medicines and 250 methods of analysis for the identification or quality control of these substances; a collection of 1500 reference substances required for testing is also available to users of the European Pharmacopoeia. This highlights well the constant evolution of the European Pharmacopoeia.

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Coordination of anti-doping policies: a public health matter

The Council of Europe's Anti-Doping Convention (ETS 135) was drawn up in 1989, at a time when doping was not yet in the spotlight, and when combating doping was largely a matter for sports organisations. There was already a wish among states at that time to protect sportsmen and women, for public health reasons, and to preserve the ethics of sport. There were in fact various policies encouraging people to get active through sport (health, social integration, participation and education policies among them), and the authorities wished to prevent sport as a whole from being brought into disrepute by doping.

The Convention is intended to bring about international co-operation on a harmonisation of rules, the development of public-private sector partnerships for national anti-doping programmes, the prevention of trafficking in doping substances, action in the educational sphere, etc. These principles have proved their relevance, underpinning the setting up of the World Anti-Doping Agency (WADA) and the drafting of the World Anti-Doping Code. The Council of Europe Convention takes a responsible approach to the doping issue, striking a balance between measures specifically aimed at elite sport and measures relating to organised sport in its entirety, and even to society as a whole (information, education, restriction of the availability of doping substances).

The campaign against doping is intimately linked with developments in science, and the technical challenges are never-ending (detection of new substances, improvement of regulations, etc.). WADA, which brings together on an equal footing representatives of states and of sports organisations, deals very expertly with

these aspects. The main challenge at present in the intergovernmental co-operation field is that of extending the fight against doping, bringing as many states as possible into the fold. It is to be hoped that the Convention being prepared at UNESCO will meet this challenge without diminishing too greatly the level of commitment. In addition, public anti-doping policies should enable the scope of the fight against doping to be extended to those sports organisations not yet associated with this worldwide movement. Lastly, care must be taken to ensure that such policies are targeted not just at the elite athletes who have the highest profile, but also at everyone who resorts to doping. It is far from being the case that doping substances are used only by champions, as is clear from the findings of the European School Survey Project on Alcohol and Drugs (ESPAD).

The adoption of such an approach to combating doping is not automatic, for it clashes with widely held images and common behavioural patterns in our societies (particularly where the use of medicines is concerned), as well as with the unconditional attachment of importance to performance and the feeling that it is vital to keep up appearances. In order to raise these questions, an integrated approach will have to be taken, extending beyond the traditional framework of anti-doping efforts, but this is the price that governments will have to pay if they are to help to solve the public health problem, digging deeper than the tip of the iceberg represented by elite sport.

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The case law relevant for health issues

The European Court of Human Rights supervises compliance with obligations that states undertook under the 1950 European Convention on Human Rights and Fundamental Freedoms. It is competent to examine individual petitions brought by persons claiming to be victims of violations of the Convention rights by acts or decisions of national public authorities. This right of petition is a cornerstone of the Convention system.

The scope and content of the Convention rights have been fine-tuned in thousands of decisions and judgments that have been rendered since the Convention came into force in 1953.[1]

The text of the Convention does not address directly any specific health issues. Neither does it guarantee a right to health protection as such. However, many health-related matters have so far been subject to the Court's scrutiny.

There is no right under the Convention to any given standard of medical care. However, Article 2 (right to life) puts a positive obligation on States to protect life and this may include the obligation to provide adequate public health care. Manifestly inadequate quality of care may breach this right, or may be also in breach of the prohibition of torture, inhuman or degrading treatment (Article 3), in particular where it is shown that the authorities put an individual's life at risk through the denial of health care, otherwise available to the general population.

The obligation to protect life has also a procedural element in that effective official investigation should be held when an individual died as a result of acts of state agents. In cases involving allegations of medical malpractice this obligation extends to the need for an effective system for establishing the cause of death of an individual under the care of health professionals and liability therefore.

Case-law concerning Article 5 (right to liberty and security) developed important procedural safeguards applicable in proceedings concerning detention on persons with mental health problems.

Another right relevant for health is that to respect for private life (Article 8), a concept which includes a person's physical and psychological integrity. Its essential object is to protect the individual against arbitrary interference by authorities. In addition, there may be positive obligations inherent in that right, which involve the adoption of measures, designed to secure respect for private life, even in the sphere of relations between individuals. This provision has been invoked in cases concerning availability and quality of medical care. In such cases regard must be had to the fair balance between the competing interests of the individual and those of the community. The issues involved in such cases necessitate an assessment of the priorities in the context of the allocation of limited public resources. The states enjoy a wide margin of appreciation in this respect, but their decisions are ultimately subject to the Court's scrutiny.

The Convention serves as last resort to persons whose rights have been breached by national authorities. It also provides inspiration and guidance to national legislators, as well as incentive for legal reforms, by prompting states to change laws and practices which have been found to have violated the Convention. As the Convention is a living instrument, its interpretation of the rights it guarantees evolves in time, and positive obligations of states, also in respect of health protection, have increasingly come to the fore in the case-law.

While it is not the Court's task to assess national policies as it is in the nature of its judicial function that it acts only on a case-to-case basis, it has greatly contributed to the developing of a European consensus as to human rights standards against which acts of states are measured, including in the domain of health care. The intrinsic link between health, dignity and human rights has repeatedly been highlighted in its decisions.

1) The case-law is available via the Court's database HUDOC:

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The European Union

Cooperation in the field of substances of human origin

The European Union has a long tradition in the area of substances of human origin. A Commission Communication of 21 December 1994 on Blood Safety and Self-sufficiency in the European Community identified the need for a blood strategy in order to reinforce confidence in the safety of the blood transfusion chain and promote Community self-sufficiency.

It was the entry into force of the Treaty of Amsterdam in 1997, and in particular Article 152 of the Treaty, that provided the Community with the opportunity to implement binding measures laying down high standards of quality and safety of organs and substances of human origin, blood and blood derivatives.

The direct consequence of this new legal basis has been the adoption of two new Directives: Directive 2002/98/EC of 27 January 2003 setting standards of quality and safety for the collection, testing, processing, storage and distribution of human blood and blood components and amending Directive 2001/83/EC, and Directive 2004/23/EC of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells.

The Council of Europe, in the context of intergovernmental co-operation in the field of health, has consistently selected ethical problems for study. The most important such ethical issue relates to the non-commercialisation of human substances i.e. blood, organs and tissues. The Council of Europe has extended its role to the technical field with the elaboration of guidance in this area.

It is obvious that there are a number of synergies and complementarities between the work of the two institutions and this has lead to extensive cooperation during recent years. The Council of Europe speaks authoritatively on ethical matters, but it is important that there is close cooperation to ensure coherence between the principles of the technical guides it produces which establish recommendations on best practice, and the technical requirements of the EU Directives which set out legally binding requirements.

The Council of Europe has offered its technical expertise to the Commission and played an important role in the preparation of Commission Directive 2004/33/EC of 22 March 2004 implementing Directive 2002/98/EC as regards certain technical requirements for blood and blood components.

The Council of Europe was also involved from the beginning in the elaboration of the Directive on tissues and cells. Its representatives participated in all the preparatory meetings including the Malaga international experts' Conference, co-organised by the Commission and the Spanish presidency. Following the example of the collaboration on blood with the Council of Europe, its guide on safety and quality assurance for tissues and cells will be taken into account by the Commission when establishing technical standards under Directive 2004/23/EC.

Finally, the importance of the Council of Europe as offering an intermediate step for many countries in the process of becoming European Union member states is very clear in this field. Compliance with the recommendations of the Council of Europe will help potential member states to be ready to adopt in the future the Community *acquis* on substances of human origin.

For further information, please visit following website: http://europa.eu.int/comm/health/

Fernand Sauer
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World Health Organisation

Cooperation through the Social Cohesion Initiative of the Stability Pact for South East Europe

Health is an integral determinant of social cohesion and a major factor for investment and development. It is essential to lasting peace, stability and economic development. In the South Eastern European region this remains a major challenge. Responding to the needs in this region, the Council of Europe (CoE) and WHO Regional Office for Europe (WHO Europe) decided to join forces in 2001. This is a natural partnership as both intergovernmental organizations view health as a basic human right and seek to bring equity to European health standards. As a result of this joint effort, health was put on the Stability Pact agenda.

This provided a unique opportunity to continue boosting public health and health developments in South Eastern Europe. The joint action is based on important reference points, such as the Council of Europe strategies and policies on social cohesion, health and vulnerability; the WHO Europe country strategies; the European Union's new public health strategy and the *acquis communautaire*.

A cornerstone political agreement for cooperation and action for health was reached in September 2001 when the Dubrovnik Pledge on 'Meeting the Needs of Vulnerable Populations in South East Europe", the first ever political document on regional health developments, was signed by the Ministers of Health of the South Eastern European countries. This process was facilitated and supported by the Council of Europe and WHO Europe.

Seven regional projects for over 8 million Euros were designed. Three of them (in mental health, food safety and surveillance of communicable diseases), for over 4.5 million Euros, are now being implemented. The governments of Belgium, Greece, France, Hungary, Italy, Switzerland and Slovenia support the projects both technically and financially.

Since its outset, this process has been guided by a strong sense of regional ownership and leadership. Equal responsibilities, commitments and involvement of all South Eastern European countries at both political and technical levels have been sustained in 2002-2004. This approach was further strengthened through implementing concrete activities in the health sector with practical policy and technical outcomes achieved, both nationally and regionally.

Through enhanced dialogue, respect and trust, there is agreement today between the

International organisations' cooperation with the CoE

countries despite the existing differences. Regional llaboration is strong and stable, nderpinned by a shared concept, long-term and immediate specific objectives, deliverables, approaches and echanisms. The spirit of openness, transparency and accountability in both the dialogue and actions is one of the greatest assets of this cooperation.

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Products developed, agreed and delivered by South Eastern Europe countries in 2001-2003

***Mental Health* (MNH)**

- Mental Health Policies and Legislation in SEE: The Regional Perspective
- Regional comparative Analysis of Mental Health Services in SEE
- National assessment of MNH status, policies, legislation and services
- National MNH Policies with Action Plans
- National frameworks for MNH legislation harmonized to EU standards
- Enhanced national cooperation between governmental sectors and NGOs

***Communicable Diseases Surveillance* (CDS)**

- Multinational team assessment missions
- National Action Plans for CDS
- National strategies for strengthening the national CDS system including portfolio of project proposals
- Harmonised definitions and methodologies

Food Safety

- Food and Nutrition Policy
- Food and Nutrition Action Plan

International Non-Governmental Organisations wish to share their experience

International Non-Governmental Organisations (INGOs) constantly draw the public authorities' attention to the human realities reflected in statistics that illustrate social inequalities in health. As well as exposing disparities in life expectancy, INGOs are actively involved in promoting respect for human dignity and access to the full range of interdependent fundamental rights which include housing, employment, social security, education and health: "It would be wrong to claim that we are improving the state of health of the most deprived members of society without taking account of not only the uncertain conditions in which they live, but also the inconsiderate way in which they are treated at work and the humiliation they suffer if they are made fools of or belittled by officialdom".[1)]

INGOs feel that all too little is done during the training of health professionals to promote human dignity, and even less to foster the close links between the right to health and other fundamental rights.

They also observe that health programmes are increasingly frequently based on epidemiological data, with the sole aim of improving these figures.

They deplore the fact that, as a result of the growing specialisation of medical disciplines, particularly within hospitals, health systems stand alone, incapable of establishing the necessary links with the welfare sector, or indeed with the non-hospital medical sector.

At the Council of Europe, the thirty to forty INGOs which are members of the "Health" Grouping now have participatory status and therefore wish to be systematically involved in the work of the committees of experts which draft Council of Europe recommendations in this field, in particular those concerning palliative care, health education and universal access to health care and prevention.

This joint work has already commenced, as evidenced by the *Report on Access to Social Rights in Europe*, presented at the Malta Conference (November 2002), and the contribution that INGOs were asked to make to the 7th Conference of European Health Ministers, in Oslo in June 2003, on the theme of "Health, dignity and human rights". Now that they have been granted participatory status, the INGOs hope to acquire the wherewithal to ensure that the Council of Europe takes full account of the aspirations and experience of civil society, with a view to promoting health as a genuine social right.

1) François-Paul Debionne: *La santé passe par la dignité. L'engagement d'un médecin (No health without dignity. A doctor's commitment).* Editions de l'Atelier, Editions Quart Monde, Paris, February 2000, 237p.

Further information can be found on following website: http://www.coe.int/T/E/NGO/Public/

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On 19 November 2003, two Resolutions recognising the work done up until now by non-governmental organisations at the Council of Europe have been adopted:

- Resolution (2003)8 on participatory status for international non-governmental organisations with the Council of Europe
- Resolution (2003)9 on the status of partnership between the Council of Europe and national non-governmental organisations

Georgia

The European Health Committee and its impact in Georgia

Georgia regained its independence in 1991 and has since been in transition. During the Soviet time healthcare was inefficient, but of a relatively acceptable standard and there was a sustainable welfare system. Independence was followed by a decade of post-transformation instability, ethnic clashes, and civil war, all regretfully furthermore accompanied with devastation of the state supported system of healthcare and social security. There was a deterioration of disease prevention and child healthcare structures, cancellation of state-subsidised support for pharmaceuticals and the frustration of medical personnel and their low salaries led to a drop in the quality of medical care. State healthcare expenditure has decreased from 4.5% in 1991 to as low as 0.7%-1.3% of GDP (1998-1999) - 7-12 Euros per capita. 80 -87% of total expenditure on healthcare comes directly from an impoverished population.

This difficult state of healthcare demands rapid action and profound restructuring. However, such progress needs a meticulously developed legal basis, thoughtful analysis of existing problems and changes to the regulatory mechanisms. The Council of Europe and the European Health Committee (CDSP) offers help in all these areas.

Georgia became a member of the Council of Europe in 1999. However, the first legal act on healthcare of the new state - the *Law on Health*, adopted in 1997, - was written by Georgian experts with thorough consideration of, and in full compliance with, the *Convention on Human Rights and Biomedicine*, as well as other European texts on transplantation, mental health, clinical research, euthanasia, etc. Other documents soon followed and were adopted by the Georgian Parliament – *Law on Patients' Rights*, *Law on Transplantation* (both 2000) and *Law on Medical Activity* (2001). The role of the Council of Europe in the development of those documents can not be overestimated.

The CDSP Assistance project to Georgia (2001-2002) aimed to develop a policy document on Health Technology Assessment (HTA). Health Technology Assessment has been used successfully in many countries for several years as a policy tool to improve the effectiveness and efficiency of health care systems. It is essential for a country like Georgia to learn how to use the limited resources available in the most cost-efficient way – based on scientific evidence. The principal objective of a national HTA policy is to establish a comprehensive basis for decision-making for the introduction and access of effective medical technologies at all levels of health care. It aims to ensure that, as far as possible, the HTA concept becomes an integrated part of routine decision-making for planning and operational policy within the national health care. It also provides input to decision-making in policy and practice; it is multidisciplinary and comprehensive in nature. The draft document on HTA policy has been prepared based on the joint work of local and foreign experts. After some final comments and refining by international institutions it will serve as a basis for the Georgian Government to develop instruments for better decision-making in the fields of health policy, clinical practice guidelines development, technology selection and the quality of care assessment.

There are numerous other fields in which Georgia is lucky to have guidelines and recommendations provided by the CDSP expert committees: revision of the social charter, blood transfusion, transplantation, organ donation/prevention of organ trafficking, Information technologies used for healthcare benefits (Patient and Internet), hospitals in transition, regulation of the migration of healthcare professionals, healthcare services in multi-ethnic societies, etc. Given the outstanding knowledge of experts from different countries, concentrated in the recommendations, thoughtfully matured through the process of tiered revisions in the CDSP and its bureau meetings, we can observe that countries like Georgia are gaining substantial savings of their limited funding and have access to the best basis for the transformation of the healthcare system in a timely and cost-effective manner. The new leader of Georgia – and a long-term participator in Council of Europe activities – President Mikhail Saakashvili is devoted to extending cooperation with the Council of Europe in every field, including healthcare.

We wish the CDSP another 50 years of successful and interesting work to strengthen equity and human rights in the healthcare field!

Zviad Kirtava, MD, PhD
Permanent representative of Georgia
at the CDSP and CDSP Bureau Member

Finland

Patients´ rights

Finland was the first country in Europe to adopt an Act on the Status and Rights of Patients in 1992. It came into force in 1993. The discussion about the need to have a law on the rights of patients started in the early 1980s, and the final outcome of this discussion was the law which includes all essential patients´ rights. The legal position of patients is also regulated by other laws such as the Patient Injury Act adopted in 1986 and the Medical Research Act adopted in 1999.

The Act on the Status and Rights of Patients includes the right to good health care, medical care and related care as needed, access to treatment, to be informed about treatment and care, self-determination, the status of minor patients, emergency treatment and ´the incompetent patient´. The law applies to every part of the general health care system and to health care services provided in social welfare institutions.

The main content of the Act is:

- treatment requires the consent of the patient;
- patients must, if they request, be given information on their state of health, the extent of the proposed treatment, any risk factors, and possible alternative choices for treatments;
- patients are entitled to see and correct the information entered in their own patient records;
- those on a waiting list for treatment must be told the exact estimated time for treatment and if this time has to be changed later, the new exact time for treatment and the reason for the delay;
- patients dissatisfied with their treatment are entitled to lodge a complaint with the establishment concerned.

Furthermore, establishments providing medical treatment must have a patient ombudsman, whose duty is to inform patients of their rights and to assist them, if necessary, in submitting a complaint, appeal or claim for indemnity. The opinion of young patients must be taken into account if they have reached a stage of development at which they are able to express an opinion and a child's parent or guardian is not entitled to refuse treatment that would avert a health risk and save the life of an underage person.

The National Advisory Board on Health Care Ethics (ETENE)

The Advisory Board, nominated by the Government (for the first time in 1998), deals with ethical issues related to health care and the status and rights of patients from the point of view of principle. The Board can also take initiatives and issue advisory opinions and recommendations on ethical health care issues.

In Finland, according to the Acts on Public Health (1972) and Specialized Medical Care (1989), the municipalities (local authorities) are obliged to provide the citizens with health care services. In addition, the Act on the Status and Rights of Patients regulates the right to health care and stipulates that every person who stays in Finland permanently is entitled to medical care without discrimination within the limits of the resources which are available at the time in question. It is up to the physician in charge to decide whether medical treatment is needed or not.

The Finnish Parliament is just now considering amendments to the Acts on Public Health and Specialised Medical Care, which will guarantee treatment according to the need for medical treatment within six months and as regards mental health care of young people within three months at the latest.

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Palliative care: a social right or a privilege?

When treatment is no longer possible, medicine must relieve patients' suffering and offer them general care and support.

Palliative care involves comprehensive and active care for all patients in the advanced stages of progressive diseases, the aim being to control the pain and other symptoms. Psychological, social and spiritual support are other key aspects.

Access to appropriate health care is recognised as a fundamental right. Palliative care should therefore be universally available. However, only a tiny minority of the terminally ill and dying have access to it. Apart from the United Kingdom, where provision has existed since 1967, most European countries are finding it hard to incorporate palliative care in their health systems. Why is that the case?

- Because palliative care is not yet recognised by all sections of the medical establishment;
- Because public awareness of palliative care is low;
- Because it does not receive adequate official support (for instance, it is not refunded under health insurance schemes), which can lead to the risk of two-tier health care.

Palliative care therefore faces a threefold challenge:

- The training of healthcare professionals, especially doctors. There are very few courses in palliative care for trainee doctors.
- Public awareness-raising. The public at large are either unaware of the existence of palliative care or confuse it with euthanasia.
- Legislative and financial support from political leaders (France is one of the few countries to have made corresponding legislative provisions - Law of 9 June 1999).

These three challenges apply in all member states. However, there are such great differences in the development of palliative care in the various countries that there is also another collective, supranational challenge: that of fostering greater co-operation between countries in order to reduce the disparities in the availability and quality of palliative care.

The European Association for Palliative Care (EAPC), which has been recognised as an international non-governmental organisation (INGO) holding participatory (formerly consultative) status with the Council of Europe since 1998, has been pursuing this objective for several years. It facilitates exchanges between healthcare practitioners from various countries, fosters joint research on therapeutic practices such as terminal sedation and encourages debate about the serious issues raised by difficult cases of terminal illness, including euthanasia requests. A practical guide for carers faced with euthanasia requests is also under preparation.

The EAPC was involved in the drafting of Recommendation Rec(2003)24 of the Committee of Ministers of the Council of Europe on the organisation of palliative care and is leading a joint European effort to disseminate the text. Media information campaigns, seminars and debates will serve to publicise the content of the recommendation in most European languages.

However, one must ask whether the difficulty that palliative care - whose purpose is to offer the terminally ill the best quality of life possible - is having in establishing itself is not also a result of it taking a completely different approach to illness, the terminally ill and death. With today's increasing life expectancy and population ageing, however, the development of palliative care is a key challenge for our society. We are therefore faced with a major political and ethical question: to what extent do our societies feel responsible for the quality of life of their terminally ill citizens?

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Maurice Chausson
EAPC Representative

The French Haemophilia Association

Over 6,000 people suffer from haemophilia in France. Haemophilia is a genetic condition whose existence can be traced back to ancient times to judge from the special dispensations from certain rites of passage (circumcision, various forms of scarification, etc). It prevents the blood from clotting and means that those suffering from the condition bleed much longer. In turn, wounds which might appear harmless can lead to fatal haemorrhaging and irreversible damage to the bones, tissues and nervous system.

Current treatment of the disease has completely transformed the lives of haemophiliacs. They now have a normal life expectancy with few or no complications, providing they follow regular treatment, a little like diabetics who rely on insulin. This treatment involves (i) plasma-derived products, with all the drawbacks inherent in products of human origin (the first case of contamination, syphilis, was officially recorded in 1929), although sophisticated purification methods now ensure optimum quality, and (ii) products manufactured by genetic engineering without the use of human cells.

For optimum treatment, haemophiliacs have to have regular intravenous injections; they were the first to master the techniques of self-injecting and to persuade manufacturers of the need for kits comprising everything required for injecting.

Today, provided that sufferers closely follow their treatment and manage to avoid the initial risk of developing an antibody which would make the situation much more complicated, they can live a totally "normal" life, and take part in all sorts of activities, including most sports, without any apparent medium or long-term complication.

But haemophilia has not gone away. Almost 60 babies (boys and girls) are born with the condition every year in France and there are a number of battles still to be won. These include:

- ensuring that all haemophiliacs are provided with satisfactory treatment
- educating all patients to cope with their treatment in collaboration with doctors
- systematically providing women sufferers with treatment (haemophilia among women was for many years unknown, then denied and finally acknowledged)
- finding a simple and reliable dosage for clotting factors: the lack of a suitable method is a serious obstacle to manufacture and treatment
- manufacturing treatment in sufficient quantities (world production, vastly inadequate, is about 60 kilos)
- constantly improving products and the way they are used
- carrying out more research: as always, the results of such research are of benefit to a much wider circle than just haemophiliacs and their families.

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Jean-Pierre Bernhard
President of the Alsace Haemophilia Association

European Kidney Patients' Federation (CEAPIR)

The shortage of donated organs is a crucial issue, a question of survival or of better quality of life for all patients needing a transplant. The European Kidney Patients' Federation (CEAPIR) aims to encourage the member states of the Council of Europe to ensure that organ donation promotion strategies are implemented at all levels, from the individual citizen in specific settings (schools, workplace and health care) to local and national government. Also, the public should be properly informed about the benefits of health and organ donation promotion and especially about kidney disease prevention programmes.

The European Health Committee (CDSP) is an important and leading motor in promoting health, organ donation and transplantation in Europe. Its recommendations adopted by the Committee of Ministers of the Council of Europe sets out guidelines for member states which hopefully will lead to greater unity between member states. The necessity of more unity in the field of organ donation and transplantation is self-explanatory if one looks at the European figures on organ donation and transplantation rates.

Patient organisations feel that not enough efforts are undertaken by most member states to solve the European-wide shortage of organs. This has been confirmed by our member associations at our General Assembly 2004 held on the 29-30th May 2004. In consequence, we demand that the member states of the Council of Europe should guarantee that a system exists to provide equitable access to transplantation services. An increased number of transplantations would help to reduce costs and increase efficiency.

The CDSP publications are standard setting, a useful foundation and information source for patient organisations in their daily work in the field of organ donation and transplantation. Dialysis patients and transplantees are becoming more demanding concerning their own needs and the quality of health care they receive. Their representatives are also becoming more demanding regarding their participation in decision-making processes on all levels. The aim is to fully integrate the voice of the patients from the beginning. In consequence, CEAPIR and the European Heart and Lung Federation have agreed to speak with one voice on the European level and to more intensively co-operate with the Council of Europe.

We wish the European Health Committee all the best for its future work and offer thanks for their ongoing work towards taking greater care of patients' interests.

The European Kidney Patients' Federation (CEAPIR) congratulates the European Health Committee (CDSP) on its 50th Anniversary, for the work it has undertaken and its achievements!

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Knud Erben
President of the CEAPIR

Adopted Texts

Recommendations of the Committee of Ministers:

- Rec(2004)8 on autologous cord blood banks and explanatory memorandum
- Rec(2004)7 on organ trafficking
- Rec(2003)24 on the organisation of palliative care and explanatory memorandum
- Rec(2003)12 on organ donor registers
- Rec (2003)11 on the introduction of pathogen inactivation procedures for blood components
- Rec(2003)10 on xenotransplantation *and explanatory memorandum*
- Rec(2002)11 on the hospital's and clinician's role in the optimal use of blood and blood products
- Rec(2001)13 on developing a methodology for drawing up guidelines on best medical practices and explanatory memorandum
- Rec(2001)12on the adaptation of health care services to the demand for health care and health care services of people in marginal situations and explanatory memorandum
- Rec(2001)5 of the Committee of Ministers to member states on the management of organ transplant waiting lists and waiting times
- Rec(2001)4 on the prevention of the possible transmission of variant Creutzfeldt-Jakob Disease (vCJD) by blood transfusion
- Rec(2000)18 of the Committee of Ministers to member states on criteria for the development of health promotion policies and final report
- Rec (2000) 5 on the development of structures for citizen and patient participation in the decision-making process affecting health care and explanatory memorandum
- Recommendation N° Rec(1998)7 concerning "The ethical and organisational aspects of health care in prison"
- Recommendation N° Rec(1993)6 concerning "Prison and criminological aspects of the control of transmissible diseases including Aids and related health problems in prison"

Recommendations of the Parliamentary Assembly:

- Recommendation 1661 (2004) on the Future of social security in Europe (April 2004) Recommendation 1611 (2003) on Trafficking in organs in Europe25 June 2003
- Recommendation 1626 (2003) on the reform of health care systems in Europe: reconciling equity, quality and efficiency (October 2003)
- Recommendation 1418 (1999) on the Protection of the human rights and dignity of the terminally ill and the dying (25 June 1999)

Resolutions:

- Resolution AP (2000) 1 on the classification of medicines which are obtainable only on medical prescription and Appendices (2003 edition)
- Resolution ResAP(2003)2 on tattoos and permanent make-up
- Resolution ResAP(2003)3 on food and nutritional care in hospitals
- 2004 Resolution of the Commission on Narcotics and Drugs of the United Nations on "Minimum requirements for pharmacological, psychosocially assisted treatment of opioid-dependent persons"
- Resolution 1310 (2002) on Maternity in Europe: improving social and health conditions (November 2002)
- Resolution 1367 (2004) on Bioterrorism: a serious threat for citizens' health (March 2004)

Repports and Publications

- *Guide to the preparation, use and quality assurance of blood components*, 10th edition (2004)
- *Guide to safety and quality assurance for organs, tissues and cells*, 1st Edition (2002)
- Pathogen inactivation of labile blood products (2001)
- Blood Transfusion - Half a century of contribution by the Council of Europe by Professor Bernard Genetet (1997)
- *Natural sources of flavourings*, (2000), ISBN 92-871-4324-2
- *Plants in cosmetics/Les plantes dans les cosmétiques*,Vol I, (2002), ISBN 92-871-4703-5
- *Plants in cosmetics/Les plantes dans les cosmétiques*,Vol II, (2002), ISBN 92-871-4676-4
- *Food and nutritional care in hospitals: how to prevent undernutrition*, (2002), ISBN 92-871-5053-2
- *Access to social rights for people with disabilities in Europe*, (2003), ISBN 92-871-5328-0
- *Rehabilitation and integration of people with disabilities: policy and legislation*, 7th edition, (2003), ISBN 92-871-5123-7

Calendar of meetings

Events:

- 14 June: World Blood Donor Day - Contribution of the Council of Europe (Collection of Blood and Round Table) – Strasbourg
- 18 September: 6th European Day of organ donation and transplantation – Athens

Committee Meetings:

- 15-16 June: 55th meeting of the European Health Committee (CDSP) - Celebration of its 50th anniversary – Strasbourg
- September: 26th meeting of the committee on the Rehabilitation and Integration of People with disabilities (CD-P-RR) (subject to confirmation) - Romania
- 3-5 November: 2nd meeting of Committee of experts on the education and integration of children with autism (P-RR-AUT) - Strasbourg
- 16 - 17 November: 56th meeting of the European Health Committee (CDSP) - Strasbourg
- 22-24 November: Committee of experts on universal design (accessibility) – Strasbourg

"Social Cohesion Developments" - electronic newsletter published by the DG III – Social Cohesion of the Council of Europe – special issues are published once a year – Members of the Editorial Group: Gilda Farrell (responsible editor), Head of the Social Cohesion Development Division – Maria Ochoa-Llido, Head of the Migration and Roma/Gypsies Division – Véra Boltho, Head of the Department of Health and the Partial Agreement in the Social and Public Health Field – Cathie Burton, Press Officer – Karl-Friedrich Bopp, Head of the Health Department – John Murray, Head of the Social Policies Department – Françoise Zahn (coordination, edition and layout) – E-mail : DG3.Bulletin@coe.int