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Federal Office of Public Health
Swiss National Science Foundation**

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Citizen Panel Report

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1 Introduction

The transplantation of cells, tissue, and organs confronts many individuals with difficult decisions. In the final analysis, the reflections made in reaching such a decision lead to a question of life or death. PubliForum, jointly organized by the Center for Technology Assessment, the Federal Office for Public Health, and the Swiss National Science Foundation, has given a group of laypeople the possibility of discussing various aspects of transplantation medicine with professionals from a broad array of specialized branches. The results of this debate are contained in the present report which is addressed, first and foremost, to decision-makers in the fields of politics, the economy, and scientific research.

For many of the chronically ill, as well as for those near and dear to them, the achievements of transplantation medicine represent a huge step forward, furnishing certain of them, for example, with the possibility of living their lives free from the dialysis machine (which purifies the blood by means of an artificial kidney), while providing others with the very possibility of survival, as in the case of a heart transplant. Seen from this angle, transplantation medicine bestows the gift of new life. However, save for the case of a living donor, transplants are always associated with a person's death. One man dies; another receives his vital organs. Central to this issue is the definition of death. And the "brain-dead" definition, the one by which transplantation medicine sets store when removing an organ, is not universally accepted – and sometimes, only under certain circumstances if at all.

The transplantation of organs is characterized by a wide-open gap between supply and demand with respect to suitable organs, and situated within the background of the non-negligible fact that the decision on donating one's organs, once death has taken place, requires a coming to grips with one's

own mortality. For this reason, the question often arises as to who is to make the decision concerning the removal of an organ in the absence of any prior expression of the wishes of the deceased in this respect. Should discussions be conducted in the interest of the life to be bequeathed anew? Or does the balance tip in favor of respect for those left behind mourning and for the still unfolding phenomenon of death?

Unsatisfied demand works as a catalyst for research into development of alternatives to the transplantation of human organs intact. For instance, innovative research efforts are being directed at using cells to breed fragments of skin or cartilage; others, at transferring cells, tissue, and organs of animal origin to human beings (xenotransplantation). Yet, can one consider all that is feasible as being justifiable as well? Ethical questions begin to emerge, as do biological considerations as to crossing over the boundary between species.

The practical problems of transplantation medicine are inevitably linked to questions which, in end effect, involve our self-concept, our conception of humanity, and our image of the world. Consequently, a public discussion on this topic is all the more urgently required. PubliForum's method, as elaborated by the Center for Technology Assessment, is the appropriate instrument to this end.

Mandated by Parliament, the Center for Technology Assessment (TA) deals with assessing the prospects and the risks associated with new technologies. In addition to studies conducted by experts, it's objective is that the appraisal of the "common" citizen be also taken into consideration. Inspired by the Danish "Consensus Conference" model, PubliFora are to be understood as platforms designed to get the population involved in the political decision-making process with respect to controversial issues under discussion in society. By sounding out a group of citizens as early as possible in the political process, the decision-makers are provided with valuable, qualitative indicators as to the aspects which may evoke popular dissent and those towards which a consensus can be targeted.

Having already organized two PubliFora ("Electricity and Society", 1998; "Genetic Technology and Nutrition", 1999), the TA Center conducted a PubliForum on Transplantation Medicine during the year 2000, in cooperation with the Federal Office for Public Health and the Swiss National Science Foundation. Such common sponsorship was evident in that both of these institutions are also interested in involving the general public in their on-going projects.

Legislation on transplantation is currently being drafted by the Federal Office for Public Health with the aim of solving some of the problems on the Swiss national level. The project law anticipates, among other things, the development of a model destined to replace today's disharmonious cantonal regulations on admissible procedure for removing organs from human corpses. For its part, the Swiss National Science Foundation has launched a national research program entitled "Implants and Transplants" (NPF 46) in order to promote innovative and interdisciplinary research efforts.

Willingness to dialogue

PubliFora are, in principle, based on the premise that all of the participants are ready and willing to engage in an open dialogue with each other. Not only the participating citizens in particular, but also the information persons they have chosen, as well as the members of the accompanying group – an advisory body of the organizers – must confront the challenge of re-examining preconceived opinions in an exchange of viewpoints with other individuals coming from circles beyond their normal realm of acquaintances.

A random mailing went out in April 2000, in which approx. 10,000 persons living in Switzerland received information on the PubliForum which was in the planning, along with an invitation to participate. Those who were interested were able to sign up by filling out a short biographical questionnaire, thereby simultaneously expressing their readiness to invest three weekends for this purpose. A hundred of these registration forms were sent back to the organizers. The latter then proceeded to create what would in the future be known as the Citizen Panel. They selected thirty of these volunteers taking into consideration age, sex, profession, and linguistic region so that the complexion of the group be as representative as possible.

It was only in mid-September that the members of this Panel met for the first time at a place in keeping with the topic to be discussed. The Swiss Red Cross Training Center in Nottwil served as the venue at which they became acquainted with one another, with the organizers, and last but not least, with transplantation medicine. The citizens participating had already been supplied with informational material in the form of eleven "Fact Sheets" beforehand. This had enabled them to acquire some rudimentary knowledge of transplantation medicine. At the meeting in Nottwil, three guest speakers added to the facts already in their possession. *Thierry Carrel* (Cardiovascular Surgery Clinic, Inselspital, Bern), *Dominique Sprumont* (Institute for Law on Health Issues, University of Neuchâtel), and *Christian Kissling* (Justi-

tia et Pax) delved into the medical, legal, and ethical aspects of transplantation medicine. Furthermore, there was a selection of specialized publications available to enable the participants to pursue those aspects of the topic meeting with their own personal interest on an in-depth basis.

The Panel came together a second time for a similar preparatory weekend in the Münchenwiler Castle in October. This time it was faced with the arduous task of finalizing the text of the questions it wished to discuss when the PubliForum itself would take place, together with that of determining who would be the information persons tasked with giving the replies. A great deal of patience was required as the now 28-member, extremely heterogeneous group went about honing down the questions, realizing that the time allotted during the forum itself would be too short to deal with all of the questions that emerge when reflecting upon transplantation medicine. The choice of the information persons was conducted according to a similar principle. A document with data on nearly ninety specialists and individuals concerned who had expressed their readiness to speak out and give an account, was placed at the disposal of the Citizen Panel. In making its selection, the Panel put emphasis on allowing those representing different positions with respect to each individual question, to give voice to their arguments. Thanks to this approach, when the actual forum took place, all of those present were able to take advantage of the information persons gathered together with their absorbing, complementary, or contradictory contributions. The present report is further testimony to the multi-faceted discussion which took place; the Panel has herein striven to do justice to the various points of view expressed.

An enormous capacity to engage in dialogue was thus an intrinsic requirement for the tasks which the citizens accomplished during the preparatory weekend meetings and, hand-in-hand with the information persons, at the PubliForum itself. *Ulrich Egger* (Egger, Philips & Partner) performed the job of *mediator*, a function indispensable to converting the groundwork tasks into constructive discussions. With the support of his assistant, *Laurent Salzarulo*, he made sure that all of the participants had the opportunity to introduce their opinions into the discussion and to be heard. The smooth manner in which the debates took place was also the merit of the interpreters and translators who skillfully bridged the linguistic gaps.

Behind the scenes in all of these processes stood the PubliForum *accompanying group*, presided over by *Andrea Arz de Falco* (ethics professor at the University of Fribourg). Composed of representatives from

the scientific community, politics, industry, the administration, and non-governmental organizations, its task was to assure that the PubliForum was conducted in all transparency and in accordance with objective criteria. The accompanying group made the final decision concerning the composition of the Citizen Panel, and it assisted the organizers in seeking out information persons exhibiting a wide range of competencies, as well as the experts who spoke at the first preparatory weekend. The group also lent its continual support to the Citizen Panel in all of its tasks without, however, getting itself involved in any of its concluding deliberations. It furthermore transmitted the topics for the “Fact Sheets” to the scientific journalist *Mark Livingston* who subsequently drew them up for the Panel’s use. In addition, the group submitted a list of potential information persons to the Panel based on its assessment of their suitability to reply to the Panel’s questions in the best possible manner.

Finally, in connection with the willingness to engage in dialogue, one must also mention the PubliForum website. Any and all persons interested were able to receive an inside glance at the methods used and the way it was run, along with informational materials and complementary links, by consulting the site www.publiforum2000.ch. Moreover, the site offers an Online Forum inviting all of the visitors to share their opinions with the Panel, and in general to catalyze public debate on the topic of transplantation medicine.

The PubliForum itself: main event and results

By the end of November, the moment had finally arrived and the time was ripe for the PubliForum as such to take place. Opening day keynote speakers were *Heidi Diggelmann*, President of the Research Council of the Swiss National Science Foundation, *Thomas Zeltner*, Director of the Federal Office for Public Health, and *Klaus Hug*, President of the Steering Committee of the Center for Technology Assessment. All of them expressed their congratulations to the citizens present for having agreed to participate in the project, and gave voice to their own specific expectations. Thereafter, however, all ears were attuned to the public debate between the Panel and the information persons. Hardly a person came away unimpressed by the demanding exchange and the tangible atmosphere of respect which permeated the discussions.

The two days were dedicated to the above-mentioned problematic issues associated with the donation of organs and with the more recent directions that research in the field have taken (in particular, xenotransplantation). The first set of topics was developed by representatives of health care personnel, the medical corps, and Swisstransplant (a private organization engaged in the allocation of organs in Switzerland). They related the experiences they had made within the actual situational context, and expressed their wishes with respect to the structures they would like to see in the future. The microphone was also taken by a psychologist, an ethnologist, a moral philosopher, and a lawyer. The multiplicity of intertwined factors was brought home in a particularly vivid manner by the portrayals given by those directly affected. The account of an organ recipient on his reprieve from death was deeply moving, as was that of a father who had donated a kidney for his son. Yet at the same time, the poignant story told by an information person from whose husband organs had been removed in the absence of any donor's card and without consultation of family members, was just as touching. As to the newer technologies, the principal issue was xenotransplantation. The information persons called upon here to express their position were ample proof of the wide scope within which the Panel wished to discuss these innovative technologies. The list of those invited ranged from experts in the fields of Biology and Medicine, to philosophers and religious scholars; from advocates of xenotransplantation, to opponents either simply skeptical or totally disapproving.

On the third day the Citizen Panel retired "behind closed doors" with the task of consolidating and synthesizing all of the diverse points of view, the plethora of information, and their many impressions. Each of the six working groups dealt with one of the major sub-topics discussed, summarizing the statements of the information persons, arriving at their own conclusions, and deducing therefrom their recommendations for actions to improve the situation. The working groups repeatedly met for plenary discussion, so that in all truth the result was a common product. Despite the fact that, in contrast to previous PubliFora, the questions to be dealt with had been consciously kept to a minimum, this arduous process lasted well into the wee hours of the morning. One may well wonder whether the key to creating a document with which all of the contributing editors can identify, lies in working a late-night shift.

And thus the present report gives testimony to a judicious coming to terms with diverging points of view held by others – the members of the Panel and the information persons – and with each and every individual's own set of

values. The Citizen Panel endeavored neither to hurt anyone's feelings nor to place limits on personal freedom. They strove to formulate their recommendations as consensual solutions. However, the report makes it clear that there were questions on which no unanimous opinion could be obtained, e.g., in the discussion on a xenotransplantation moratorium. Furthermore, it makes evident that on none of the issues did the citizens neglect to consider the "human dimension". When speaking about the donation of organs, for instance, they call for the creation or reinforcement of psychological services departments for the benefit not only of those directly concerned (receivers and donors) and their family members, but also for the health care personnel involved.

The process continues

On the morning that followed the night of intensive work, the enormous achievement that the Citizen Panel had performed was suitably acknowledged and praised in PubliForum's concluding speeches. During the public presentation of the report, its authors handed it over to the Presidents of the Parliamentary Committees on Social Security and Health, *Rosmarie Dormann* of the National Council and *Christine Beerli* of the Council of States. Deeply interested in the results which had been presented, the Committee Presidents both extended invitations for the Panel to visit a Committee session. The Panel was also invited by *Beat Butz* of the Swiss National Science Foundation to a meeting with the researchers of the "Implants and Transplants" research program. On behalf of the Federal Office for Public Health, gratitude to the Panel was also expressed by *Theodor Weber*, who had been impressed by the attention the members of the Panel accorded to the human dimension in their deliberations on transplantation medicine. He added that the results the Panel had obtained would be taken into account in the elaboration of the message accompanying the new law on transplantation. In the name of the Center for Technology Assessment, *Sergio Bellucci* promised that he would make it his goal to disseminate the Panel's report to a broad public.

The present document represents the points of view of the twenty-eight citizens who participated in the PubliForum held in autumn 2000. Our heartfelt thanks go out to them and to all who played a part in the PubliForum for their unwavering commitment and constructive efforts. It is our hope that this PubliForum will serve as an impetus to public debate of the many related

issues which have not yet been addressed in connection with transplantation medicine.

*Organizing Committee
January 2001*



The citizen panel

2 The Citizen Panel

<i>Name</i>	<i>First name</i>	<i>City</i>	<i>Age</i>	<i>Occupation</i>
Bäumler	Hans-Ulrich	Nidau	54	Clergyman
Cherpillod	Olivier	Belmont	43	Director
Collenberg	Chichi	Illanz	52	Nurse
Colomb	Florence	Yverdon	27	Office Employee
Cornuz	Nicole	St. Croix	38	Management Assistant
Egli	Gotthard	Derendingen	78	Retired Agronomist
Felder	Alexandra	Genève	24	Student
Fierro	Tony	Beringen	35	Sales Engineer
Gabutti	Orsola	Bedano	45	Vocational Guidance Counselor
George	Michèle	Lugano	22	Student
Hofmann	Heinz	Steinmaur	34	Investment Counselor / Financial Consultant
Huber	Kurt	Birrhard	41	Farmer

<i>Name</i>	<i>First name</i>	<i>City</i>	<i>Age</i>	<i>Occupation</i>
Kryenbühl	Doris	Jona	38	Service Sector Employee and Housewife
Lessing Kilias	Kerstin	Davos Platz	39	Social Educator and Social Worker
Leu	Marianne	Stadel	44	Housewife and Secretary
Maddalena	Silvio	Neuchâtel	59	Machine Mechanic
Marro	Evelyne	Fribourg	19	Student
Miksch	Michael	Zürich	48	Cook
Montavon	Cyril	Schötz	22	Teacher
Morand	Antoine	Cartigny	19	Student
Morand	Theres	St. Prex	39	Farmer
Pezzoli	Olivier	Nyon	22	Student
Piguet	Pierre	Genève	61	Cinematographer
Rommel	Erna	Bern	65	Retired Secretary
Rüegsegger	Emma	Bülach	58	Scientific Collaborator
Schmid	Regula	Heimiswil	24	Veterinary Assistant
Stawinski	Andreas	Stetten	39	Company Manager
Vodola	Michele	Riva San Vitale	40	Plasterer

3 The Citizen Panel Report

3.1 The Definition of death

3.1.1 Question

In your opinion, at what stage in the dying process may / should organs be removed? Once this issue has been clarified, to whom should the decision belong, and on what criteria should it be based?

Replies of the information persons: citizen panel resume

Dying is a process during the course of which an irreversible loss of cerebral functions sets in. Referred to as “brain dead” in common parlance, this is the stage at which the scientific and medical communities judge that it is possible to remove vital organs. Once this stage has passed, certain organs, such as the heart, are unable to withstand the consequences of circulatory arrest. They begin to deteriorate, and are no longer suitable for transplantation. It is essential to note that this criterion is applied solely in this precise situation, one for which it proves indispensable.

Scientific studies have shown that whenever an accurate diagnosis of brain death has been pronounced, the possibility that the brain recuperate its vital functions can be excluded. A certain method is applied in making this diagnosis, and special instruments are used by two independent physicians

who are professionally qualified and extraneous to the process of transplantation in question. In Switzerland, these criteria have been established by the Swiss Academy of Medical Sciences, inspired by a model developed at Harvard. In addition, they have been used as points of reference in pertinent legislation in the majority of western countries, and are alluded to in the draft Federal law on transplantation.

And yet, this diagnosis remains the object of some more or less distinctive doubts, in particular, those linked to the heavy emotional content of the moment: judging by appearances, a brain-dead patient looks no different from one lying in a coma. His body is warm, he is breathing, and his heart is beating, albeit assisted by machines. In all truth, such a patient is inconsistent with the generally held image of one who is dead.

Moreover, a rational observation based on the data provided by instruments, does not permit one to take into account the spiritual dimension which, for many individuals, is of paramount importance. Indeed, not everyone agrees with the theory that the brain is where consciousness dwells. The question then arises as to how this “soul” reacts when organs are removed.

One must also take into consideration the fact that the removal of organs interferes with the natural process of death, and disturbs the mourning process of the family members. The latter confirm the trauma inherent in abandoning a loved one as a patient unmarked by the signs of death, and waiting for the hospital to call announcing that he has “finally passed away”.

Opinion of the citizen panel

With the exception of one Panel member, all of us consider that brain death is a reasonable criterion and is sufficient to allow for the removal of vital organs as long as all of the other conditions are fulfilled. The diagnosis must be guaranteed as being reliable.

It is important to keep in mind that the notion “brain dead” refers to one sole stage in the overall process of dying, and that it is employed uniquely in connection with transplantation medicine. When death is determined on the basis of this criterion, it is inconsistent with the conventional view of what is known as death.

Nonetheless, each of us is entitled to harbor a doubt in function with his beliefs and feelings. Even if one considers a diagnosis of brain death as one which is objectively certain, one still cannot equate brain death with the death of the human spirit. In this context, respect for an individual's personal convictions is indispensable.

Recommendations of the citizen panel

Recommendations made to the Swiss Federal Council (government) and to Parliament:

- The law on transplantation should provide for a provision entrusting the Confederation with the task of educating the population so that each and every citizen be able to make an informed decision and be capable of realizing the consequences which removal of organs may have on the natural process of dying.
- The term of "brain dead" leaves much to be desired and elicits misunderstanding. It would be advisable to replace it by "irreversible loss of cerebral functions" in the text of the law.
- The law should make provisions for a psychological support unit in every hospital, whose tasks should also include the dissemination of information to the donor's family members before, during, and after organ removal.

Recommendation made to hospital administrations:

- We would encourage hospitals to set up the above-mentioned support unit without waiting for the law on transplantation to enter into force.

3.2 Viewpoint of the persons concerned

3.2.1 Question

How are the lives of live donors, recipients, and relatives affected by transplantation?

- *What is their psychological state before and after the transplantation?*
- *What is their physiological state before and after the transplantation?*
- *How is the quality of life changed after the transplantation?*

Replies of the information persons: citizen panel resume

“A transplantation is a gift of time.”

This was the message transmitted to the PubliForum by information persons intimately concerned, at the beginning of the question and answer period. Based on their own true-life stories as donor and / or receiver, both of these information persons assisted us in taking note of the following facts regarding transplantation medicine.

The period prior to a transplantation is characterized by a good deal of uncertainty as to receiving a suitable organ before it has become too late. This, in turn, leads to a situation of psychological stress, while at the same time creating a mood of hope in the patient that the intervention will be crowned by success. The daily confrontation with the prospect of death precludes the possibility of making long-term plans for one's life. Given this fact, the time spent awaiting a transplantation represents an overwhelming psychological burden both for the recipient and for his or her entourage.

In addition, there is also a huge physiological charge to be borne, particularly in the case of the chronically ill, as a function of the medicinal and other therapies they must endure. For such persons, the quality of life lies on a radically reduced level (in consideration of aspects such as vacations, diet,

profession, family-life, sports, etc.). Family members and relatives are also affected to a high degree.

The quality of life markedly increases following a successful organ transplantation, and enables the patient to “lead a normal life”. It once again becomes possible to look towards the future with optimism (marriage, family, career, etc.). Just the same, the receiver remains under a certain pressure, just as do his family members, because of the medical treatment follow-up, for instance. Due to the fact that the life expectancy of the new organ is limited in time, there continue to exist other uncertainties. Even once an organ has been donated, the live donor still remains subject to residual risk since an organ is missing. As long as the donor remains in good health, this risk can be ignored; should he, however, fall ill, depending on the circumstances, the risk can be enormous.

In connection with organ donations from brain dead patients, one of the information persons expressed the opinion that a certain amount of transparency is needed to be introduced on the part of the psychological and medical personnel to allow the relatives of the brain dead donor to obtain information about the condition of the receiver and to learn whether the transplantation was successful or not. Such information can be important in helping the family members get through the period of bereavement.

Opinion of the citizen panel

- It is urgently necessary that the time span prior to a transplantation be used for confidence-building between the (live) donor / receiver and the medical team (e.g., nurses, doctors, psychologists, etc.). Subsequently, such confidence-building should be extended to include the family members.
- Both the physiological and the psychological well-being of the live donor / receiver must exist to a similar degree so as to maximize the transplantation’s chances of success.

Recommendations of the citizen panel

- The information given must be tailor-made to comply with the individual needs of the donor / receiver so that the confidence-building process can take place.
- Psychological care must be significantly reinforced.

3.2.2 Question

What experience has accumulated from the perspective of health care personnel

- *in caring for the patients (donors, receivers)?*
- *in their relations with family members?*
- *in their contacts with the authorities, private institutions (e.g., Swisstransplant), etc.?*

Replies of the information persons: citizen panel resume

The psychological burden for health care personnel varies according to whether they are charged with looking after and caring for brain dead patients, or those destined to be receivers.

a) Care of donors

The possibility that health care personnel be required to enter into conflict situations with the family members is extremely high given the fact that for the latter, the emotional content (respectful devotion) of the moment predominates. The announcement that the patient has passed away coupled with the simultaneous request for the donation of an organ, is a situation shrouded by ambivalence.

For health care personnel, caring for brain dead patients is a considerable burden in that the brain dead are in fact still in the process of dying and thus

evoke, for both the personnel and for family members, the image of living human beings.

b) Care of receivers

The consolidation of mutual confidence between the patient and the health care personnel is a prerequisite for successfully caring for and assisting receivers. Just as important is the medical team's competence in transmitting factual information concerning the operation's preparatory stages and the intervention itself.

Caring for receivers is perceived as a constructive task for health care personnel since the patient begins to prepare himself for a new future. As one doctor stated, once the transplantation is over, he continues to follow up the same patient and assumes the function of his family doctor. This approach assures the continuity of medical care together with that of mutual confidence.

According to the statements of the information persons, cooperation between doctors, hospitals, and the Swisstransplant organization is running smoothly.

Opinion of the citizen panel

The relationship between all of the parties involved in a transplantation is extremely demanding and measures must be undertaken, above all in the domain of psychology, to facilitate contact.

Recommendations of the citizen panel

- Acceptance of the procedure on the part of the general population should be promoted by way of maximum possible transparency in the matter of transplantation medicine (e.g., information campaigns, public discussions on the topic, etc.).
- In order to insure trouble-free, interdisciplinary cooperation, we recommend that special training be given to health care personnel (e.g., techniques of conducting dialogue, crisis management).

- To promote sensitization and certainty of approach in dealing with brain dead donors and their relatives, it is necessary for the health care personnel to be psychologically accompanied and advised. This would also serve to relieve the strain under which they have to work.



The citizen question the information persons

3.3 Allocation of organs

3.3.1 Question

What form might the organization of organ allocation take, and how could the legal aspects be regulated in order to guarantee fair and just allocation?

- *Who should make the decision?*
- *What criteria should be considered?*
- *Should decisions on allocation be made in a decentralized manner or in a central office?*

Replies of the information persons: citizen panel resume

a) Who should make the decision?

There are two decisions which have to be made with respect to the allocation of organs. The first one pertains to including the patient's name on the waiting list. The second decision concerns the allocation of organs to receivers.

The first decision (inclusion on the waiting list) is made by a team comprised of doctors, nurses, and psychologists. Studies have shown that the professionals make more sensible decisions and react more rapidly than do commissions composed of laypeople.

There are still other persons involved with regard to the second decision. As soon as an organ is available in a transplantation center, the news is reported to Swisstransplant. Next, the "Super Urgent" list is checked to see whether it includes any appropriate patient who could be considered as receiver. If not, the organ is offered to the center in which the donor is located. Should there prove to be no suitable receiver complying with all of the conditions for transplantation among the patients in that center,

Swisstransplant offers the organ to other transplantation centers, one after another. Each transplantation center has a coordinator responsible for checking out whether there is a patient waiting for such an organ in his location.

b) What criteria should be considered?

The criteria for inclusion on a waiting list differ from those which apply to organ allocation.

In the first case, the information persons plead for a number of criteria to be handled properly. Along with medical criteria, psychosocial criteria (e.g., depression, addiction, etc.) are also taken into account. As a rule, the evaluation of psychosocial factors serves not so much to exclude patients from the waiting list as it does to identify elements of risk, and hence to trigger the application of complementary or supportive measures such as psychotherapy. A patient's status on the waiting list is subject to review at regular intervals.

As regards organ allocation, the information persons are unanimous in their opinion that first and foremost, medical criteria should play the decisive role. The time spent on the waiting list is also a factor to be taken into account. In accordance with the Federal Constitution, no room is allowed for any type of discrimination (e.g., origin), something which is not always easy to achieve in practice.

c) Should decisions on allocation be made in a decentralized manner or in a central office?

At first glance, central allocation appears to be the fairest method since all patients are treated equal. However, since fairness is oftentimes not to be equated with equality, patients whose situation is considered as extremely particular may not be able to be taken into consideration. Central allocation would in this case be unfair to such patients.

As one of the information persons pointed out, Switzerland's transplantation centers have become specialized according to various types of transplantation. And so the scenario arises in which a patient might possibly not be admitted to the transplantation center nearest him because of a special accompanying illness. On the other hand, however, there exists

another center which is specialized in transplantation on such patients. In a system where decentralization is the rule, the patient would then have the opportunity of receiving a transplant just the same.

For this reason, the information persons recommend a decentralized system of organ allocation to the transplantation centers via a national coordination office.

Opinion of the citizen panel

The Citizen Panel supports the position that a professional team composed of doctors, nurses, health care workers, and psychologists should make the decision on who should be included on the waiting list. We hold this opinion due to the fact that, for one thing, these individuals are well acquainted with the patient, and thus both professionalism and efficiency are equally assured their place in the decision-making process.

A patient's autonomy to refuse an eventual transplantation should be kept in mind. And should he already be on the waiting list, his refusal should entail no negative consequences.

Similar to that of the information persons, it is also our opinion that both medical and psychosocial criteria should be applied in including patients onto the waiting list. We judge it important that the criteria of the individual transplantation centers be in harmony with one another.

As to the allocation of organs currently being effectuated by Swisstransplant, we believe that we should continue along the path taken up to now. This means that allocation of organs should be conducted according to a decentralized system. The reason for this is that Swisstransplant is generally recognized as having been doing a successful job for several years already. Furthermore, it appears to us that this Organization performs efficiently and executes its mission in an appropriate and dedicated manner.

As a further remark, we are of the opinion that in allocating organs, primary consideration should be given to medical criteria.

Recommendations of the citizen panel

- Psychosocial aspects should also be taken into consideration in deciding on whether or not to include a patient onto the waiting list. On the basis of this premise, additional resources may have to be made available to insure that hospital personnel are competent in the corresponding areas of psychology.
- The Swiss Confederation should take appropriate measures to insure that the criteria applied for inclusion on the waiting list are consistent in the individual transplantation centers and that they are implemented in a compliant manner. This task can also be delegated further on.
- Since the allocation of organs by way of Swisstransplant has proved its worth, we would recommend maintaining the system according to which organ allocation has taken place until now. However, an appropriate system of control should be introduced.
- In the allocation of organs, primary consideration should be given to medical criteria.

3.4 Regulation of donation

“In its most profound and solemn human dimension, a donor’s prior consent before his death sustains a systematic and systemic union with the symbolism of a gift. Today’s discussion represents an exceptionally sensitive endurance test for this union” (Prof. Denis Müller).

3.4.1 Question

What set of regulations befits the dignity of the donor, and what rights should be accorded to his relatives?

Replies of the information persons: citizen panel resume

All of the speakers unanimously agreed that the explicit prior consent solution gives the best guarantee for respecting the dignity of the donor. The critical point lies along the tightrope spanning donation and removal, that is to say, the issue of personal freedom and that of solidarity with the receiver of the organ.

Top priority should be accorded to respecting the will of the potential organ donor. His or her decision on how the dying process is to unfold should be decisive since the removal of an organ is an extraneous factor intervening in the evolution of the dying process.

In the event that there exists no explicit expression of the person’s will, the family members should have the right and the duty to make a decision on behalf of the potential donor. This extended consent solution is positive in that it fosters an increase in the number of donors. The negative side is that it places an enormous burden on the relatives in that while engaged in the process of mourning, they are simultaneously called upon to make a decision on an organ donation as well.

The presumed consent solution is regarded as being rather questionable in that organs are removed without the intervention of a prior decision by either the donor or his family members. Ethical reservations exist with respect to the individual's freedom of decision. The main argument in favor of the presumed consent solution is the allegedly greater availability of donor organs. Yet one may well ask whether in all truth more organs are available as a result of this approach. In cantons and states in which the presumed consent solution is enshrined in existing legislation, it nonetheless turns out that the extended consent solution is the one which, in end effect, is practiced in the majority of cases.

Opinion of the citizen panel

The explicit prior consent solution would, in our opinion, be best in keeping with the dignity of the donor. This solution guarantees that no actions are taken contrary to the person's wishes. Furthermore, the receiver can rest assured that the donation was made on a voluntary basis. Without an obligatory registration of donors, however, this solution would pose a problem since the already acute lack of organs would possibly become worse.

In view of the already existing penury of organs, it appears that the extended consent solution is the more satisfactory option. Its disadvantage lies in the fact that already in the grips of a most difficult situation, the family members are required to pass judgment for or against donation of an organ. The agonizing question of whether or not they finally made the right decision also continues to weigh upon many of them well after the initial period of mourning.

We come out firmly against the presumed consent solution, be it in terms of presumed personal consent or presumed extended consent, since in both cases the dignity and the freedom of the donor is not guaranteed. In our point of view, this results in too much responsibility being imposed on the health care personnel.

Recommendations of the citizen panel

The Citizen Panel is convinced that a regulation of donation on the national level is essential. Although the explicit prior patient consent solution respects the dignity of the donor to the highest degree, we would recommend that Parliament incorporate the extended consent solution into the law on transplantation in view of increasing the availability of organs.

The Citizen Panel is seriously concerned in seeing that the general population be better informed on transplantation medicine so as to enhance transparency and increase the willingness to donate.

It appears that medical personnel exert significant influence on the willingness to donate organs. For this reason, we would recommend that stronger emphasis be placed on training them in the area of communication and in dealing with family members.

3.4.2. Question

What is to be thought about a regulation that demands that each and every person decide whether he or she is prepared to donate their organs?

- *Are the costs implicit in such a regulation bearable?*
- *How can such a regulation be implemented (e.g., by creating a central donor register)?*

Replies of the information persons: citizen panel resume

In general, the information persons hope that confidence will be built up by clear and open information being imparted to the population and by an increased transparency in relation to transplantation medicine. Only in this way can decision-making take place on the basis of free will and without having to resort to coercion.

The viewpoint expressed by the lawyer is that the individual should not be put under the pressure of opting for or against donation. It is his conviction that any coercion with respect to transplantation medicine can only cause harm. Still another problem would emerge in the event that sanctions be applied should an individual refuse to choose.

One of the information persons indicated that he would be in favor of making a decision in the matter obligatory, provided that in addition to agreement or refusal to donate, the possibility exist not to be forced to take a stand as well as to be able to change one's mind on the issue.

In this connection, it would be interesting to place oneself in the position of a receiver and ask: Would I be willing to receive an organ?; and if so, then should I not also be willing to donate one?

a) Are the costs implicit in such a regulation bearable?

Understood as the financial expenditures, the costs depend on the form which this regulation would take. All of the information persons deem the costs to be irrelevant.

b) How can such a regulation be implemented (e.g., by creating a central donor register)?

A central donor register could be a possible solution, keeping in mind that continual supervision and up-dating would have to be assured. The advantage is that an expression of one's desire is thereby documented in a reliable manner and is rapidly retrievable. Privacy of the personal sphere and data protection must be guaranteed.

Opinion of the citizen panel

This type of regulation would offer numerous advantages, such as:

- Avoiding misunderstandings and abuses
- Fostering debate on the topic of death in today's day and age

- Enhancing transparency through information and education of the population in the domain of transplantation medicine;

...but would also give rise to some potential problems, for instance:

- Too much interference in the sphere of personal privacy
- A tutelage situation in which decisions are made for the citizen
- The negative circumstantial aspect of coercing a decision under pressure which, in addition, could possibly risk casting a shadowy light on transplantation medicine.
- The guarantee of data security.

As regards the implementation of such a regulation, we concur with the opinion expressed by the information persons and take into consideration the creation of a central donor register. In addition, a cost-benefit analysis would have to be conducted.

Recommendations of the citizen panel

- We would recommend that the establishment of a central, voluntary donor register be examined and that the costs stemming therefrom be verified.
- In the longer run, we would hope that in actual fact, these measures culminate in an explicit donor prior consent solution, thereby obviating the necessity of legal grounding.

3.5 Research

3.5.1 Question

On the basis of what criteria should research projects, in particular those which are subject to public controversy (such as embryo research, xenotransplantation, etc.), be fostered or not? How significant a role should be played by criteria which are of an:

- *ethical*
- *medical*
- *social*
- *economic, or*
- *political nature?*

Replies of the information persons: citizen panel resume

Ethical criteria are the first which must be taken into account. Rooted in facts established in practical experience, they represent the source from which all the other criteria evolve. Situated at the crossing point of all the other disciplines, ethical considerations must be seen as the basis of all discussion and implementation of research programs, be they clinical or purely fundamental in nature.

Medical criteria comprise several clusters. It is paramount that not only the risks associated with research projects be assessed, but also their feasibility and their utility, all the while keeping in mind the fragile relationship between the principles basic to the autonomy of the individual and the scientific goal of relieving the pain of human suffering.

Social criteria are extremely close to these concerning ethics. Indeed, both of them deal directly with society in its broadest sense. They enable us to take a moral position, and are intimately linked to the utility of research projects inasmuch as the latter are destined to serve the common weal, i.e.,

society. They equally serve as an expedient enabling us to measure the degree of popular emotion elicited by certain paths which research has taken.

By reason of their huge diversity, economic criteria are also inherent in the matter. In all truth, both research and the application of its results evolve as a direct function of financing. It is therefore essential not only that the demands of the economic circles be rapidly exposed, but also that the consequences of regulations be taken into account as factors able either to attract or repel scientific capital.

There still remain political criteria. These serve to create a regulational framework and, like economic criteria, sometimes to orient research projects in a certain direction. In contrast to what takes place in financial circles, political criteria should function as a type of guardrail acting in synergy with all of the other criteria.

However, spotlighting the principal criteria should not allow us to forget that our considerations are put into practice on a multidisciplinary level. For each and every research project, characterized by its own unique particularities, all of the partners concerned strive to assess, in the most appropriate manner, the risks and benefits that society may derive from it. And whenever international research projects are carried out, these considerations must even be conducted on a supranational level.

Opinion of the citizen panel

One must reflect on one's own mortality and on the purpose of life. Human beings are not eternal, and to experience pain is part and parcel of the human condition. It is necessary to face up to the fact that this is the way life is. For its part, research should not foster the dream of immortality.

Liberty exists only within certain limits (one of these limits being, for instance, the instrumentalization of human beings). In order to avoid that things get out of control, one must be ready to withdraw at that point in a process of research where the paths have gone astray.

Animals have their own intrinsic worth and should be subject to respect. This excludes certain modes of conduct when dealing with them. Other research

approaches, such as stem cell research, could be promoted as long as the manner of acquiring them is consistent with the principles of ethics. Indeed, these other approaches are advantageous in that they are not limited solely to the domain of transplantation medicine, but also permit progress on a broader therapeutic plane (cancer, Alzheimer's disease, etc.).

From time to time, the argument is brought forth that abandoning this or that type of research would cause the flight of top specialists from Switzerland. This reasoning can be countered by stating that Switzerland could in fact be playing the role of pioneer by concentrating its research efforts in those areas which are in harmony with ethical values.

We wondered whether it might not behoove us to envisage another legal framework for research without interfering in the principles of freedom so dear to those dedicated to research (issuing ordinances instead of a Federal law).

It strikes us as important that freedom be guaranteed to research scientists so that the research process is not brought to a standstill, and so as to preclude the economy's invasion of the decision-making process (for instance, patenting of life forms).

Recommendations of the citizen panel

- Refusal to envisage in the future law, the amalgamation of legislation on transplantations with legislation on research in the field of xenotransplantation.
- Anticipation of extending the law into an international framework.
- Creation of an ethical code of conduct for researchers in order to coordinate the activity of scientific research on an international scale (WHO), with the objective of a binding commitment.
- Efforts to be made by the government to inform and sensitize the population with respect to ethical considerations and moral values implicated in research.
- A moratorium should not be used as a solution to postpone making a decision on prohibiting research.

3.6 Xenotransplantation

3.6.1 Question

What do you judge as being the health risks, the advantages, and the ethical implications of xenotransplantation?

- *How can these health risks be recognized and, if necessary, be ruled out?*
- *What alternatives exist to xenotransplantation, and what is your assessment of them?*

Replies of the information persons: citizen panel resume

a) What do you judge as being the health risks, the advantages, and the ethical implications of xenotransplantation?

Advantages of xenotransplantation in the event that animal organs should ever be able to prove a valid alternative to human organ donations:

- Sufficient supply of organs for transplantation (i.e., no waiting list).
- It would be possible to allocate organs uniquely on the basis of medical necessity.
- An operation could be planned ahead of time, thus improving the prospects for a successful outcome (alleviation of the situation of stress experienced by the prospective receiver).
- Elimination of any sentiment of guilt with respect to the human donor.
- The foundation would collapse from under any trafficking in human organs (for instance, in third-world countries).
- Even if xenotransplantation were used only to bridge time while waiting for a human organ to become available, more waiting-list patients would be able to survive for a longer period of time.

Health risks:

- A risk of infection is present: illnesses as yet unknown could be passed on to the human race.
- It is to be anticipated that stronger types of medication will probably be necessary to suppress organ rejection.
- To date, there is hardly any knowledge available as to the longer-term functioning of animal organs in the human body.
- The already known psychological problems related to transplantation could be aggravated with the advent of xenotransplantation; other, new problems could emerge as a consequence of using animal organs.
- The risk of psychological rejection based on cultural or religious motives still remains to be examined.

On the basis of these health risks, some of the information persons call for a moratorium on xenotransplantation.

Ethical implications:

- Should we as human beings be allowed to degrade animals to the level of spare-parts suppliers?
- In certain religions, the transfer of an animal organ is barely conceivable. In Islam and Judaism, for example, pigs are considered as being unclean animals.
- One of the information persons felt that a problem lay in the spreading out of animal cells in the human body once a xenotransplantation has successfully taken place (“mixture” of man and animal).
- In the event that xenotransplantation would be able to be practiced only for the purpose of bridging the time until the transplantation of a human organ, then the deficit of human organs and the problems therewith associated would only be exacerbated.

b) How can these health risks be recognized and, if necessary, be ruled out?

Animals are to be brought up in an absolutely sterile environment, and the organs programmed for donation could be tested for known pathogenic agents. The possibility that unknown pathogens are present, cannot be excluded. The animals can be modified by genetic technology so that organ rejection may be suppressed.

c) What alternatives exist to xenotransplantation, and what is your assessment of them?

In terms of rapid implementation, the following alternatives are recommended:

- Prevention
- Augmenting the willingness to donate
- Fostering living donation.

Deemed as long-term, highly promising alternatives for the future (and for which the time required up to the moment of practical implementation is judged as being comparable to that necessary for xenotransplantation), are the following techniques:

- Artificial organs (for instance, the mechanical heart), which are already at a comparatively advanced stage of development
- Research into the etiology of illnesses that lead to an organ's failure to function
- Tissue engineering
- Stem cell technology.

Opinion of the citizen panel

The risk of infection exists for the entire population, not only for the receiver of an animal organ. It is not to be excluded the retroviruses coming from the cells of pigs be capable of triggering illnesses in human beings, thus leading to the possibility of an epidemic breaking out.

In no way should psychological problems following a xenotransplantation be underestimated or tossed off as harmless. We judge that crossing over the boundary between species is a step onto territory strewn with problems.

In the opinion of the Citizen Panel, the advantages mentioned by the experts are hardly capable of offsetting the extensive risks. We therefore place an enormous amount of emphasis on the alternatives listed by the specialists.

Furthermore, a clear majority of the Citizen Panel supports the following statement:

The conditions for raising “donor animals” is fully at odds with the appropriate manner in which the animals should be brought up. We judge the genetic manipulation required on pigs in order to lessen the threat of organ rejection to be morally questionable. In our opinion, an animal should not be reduced to the level of a spare-parts supplier.

In addition, 5 members of the Citizen Panel are in favor of a moratorium on all research activity in the domain of xenotransplantation; 5 members advocate a moratorium only with respect to clinical experiments; and 14 members want no moratorium at all since they judge the legal conditions to be adequately severe.

Recommendations of the citizen panel

The Citizen Panel attaches great importance to the above-mentioned alternatives in order to alleviate the penury of organs.

- In particular, prevention should be reinforced. Damage to organs could be diminished by leading a healthy way of life.
- In order to increase the amount of donor organs available, the possibility of making living donations should furthermore not be too severely limited by legal stipulations.

In addition, we would recommend:

- Fostering the further development of artificial organs (for example, the mechanical heart) to a greater degree
- Intensification of research into the causes of illnesses that lead to an organ's failure to function
- Promotion of human tissue engineering.

Finally

- The legal provisions on xenotransplantation and on clinical experiments being planned for in the draft law on transplantation appear to us to be sufficient. This is the reason why a majority of the Citizen Panel does not call for a moratorium.
- In any event, the anticipated rules and regulations concerning civil liability (e.g., statute of limitation and the obligation for insurance) should be made somewhat more strict.
- Then too, no mention is made of any article requiring the written consent of a xenotransplant receiver.



Hearing of the information persons

Appendix I

PubliForum Order of Events / Program

First Preparatory Weekend Nottwil, 16 / 17 September 2000

Saturday, 16 September

- 10:00 – 11:00 **Introduction**
Organizers and participants introduce themselves
- 11:00 – 11:30 **PubliForum Transplantation Medicine**
What's a PubliForum all about?
- 11:30 – 12:30 **Transplantation Medicine: questions, fears, hopes**
Discussion in working groups
- 12:30 – 14:00 Lunch
- 14:00 – 15:00 **Transplantation of organs, cells and tissue: who, when, what and how?**
Lecture by *Thierry Carrel*, Director of the Cardiovascular Surgery Clinic,
Berne University Hospital
Questions and discussion

- 15:00 – 16:00 **Ethical Aspects of Transplantation Medicine**
Lecture by *Christian Kissling*, Swiss National Commission Justitia et Pax
Questions and discussion
- 16:00 – 16:30 Coffee break
- 16:30 – 17:30 **Legal Aspects of Transplantation Medicine**
Lecture by *Dominique Sprumont*, Assistant Director of the Institute for Law on Health Issues, University of Neuchâtel
Questions and discussion
- 17:30 – 17:45 Break
- 17:45 – 18:30 **How PubliForum works**
The organizers explain the main order of events and rules
Plenary discussion
- 19:00 Dinner and free time

Sunday, 17 September

- 9:00 – 9:30 **Rules, Continuation**
Plenary discussion
- 9:30 – 10:30 **What questions would we like to deal with during the PubliForum?**
Discussion in working groups
- 10:30 – 11:00 Coffee break
- 11:00 – 12:00 **What questions would we like to deal with during the PubliForum?**
Collection of the results of the working group discussions
- 12:00 – 14:00 Lunch
- 14:00 – 14:30 **Looking at the further course of events**
Choice of Information persons; meeting with the accompanying group; contacts with the media
- 14:30 – 16:30 **What questions would we like to deal with during the PubliForum?**
Plenary discussion
- 16:30 – 17:00 **Summary of the weekend**
- 17:00 End of the first preparatory weekend

Second Preparatory Week–end Münchenwiler, 21 / 22 October 2000

Saturday, 21 October

- 10:00 – 10:30 **Introduction: state of progress**
The day's organization
- 10:30 – 11:00 **Posing questions, evaluation of answers, writing a report: a short introduction**
Lorenz Hess, Federal Office of Public Health, Head of Public Relations
- 11:00 – 12:30 **Which questions are to be dealt with during the PubliForum?**
Discussion in working groups
- 12:30 – 14:00 Lunch
- 14:00 – 16:00 **Which questions are to be dealt with during the PubliForum? Continuation**
Plenary discussion
- 16:00 – 16:30 Coffee break
- 16:30 – 18:00 **Which questions are to be dealt with during the PubliForum? Continuation**
Plenary discussion
- 18:00 – 18:30 **How to address Parliament?**
Pierre-Alain Gentil, Member of the Council of States, Canton Jura
- 18:30 – 19:00 **Summary of the day and preparation for Sunday**
- 19:30 Dinner and free time

Sunday, 22 October

- 9:00 – 10:30 **Which information persons should be chosen?**
Discussion in working groups
- 10:30 – 11:00 Coffee break
- 11:00 – 12:30 **Which information persons should be chosen?**
Plenary discussion
- 12:30 – 14:00 Lunch
- 14:00 – 15:30 **Which information persons should be chosen? Continuation and conclusion**
- 15:30 – 16:00 **Which questions are to be dealt with during the PubliForum? Definitive wording and translation**
- 16:00 – 16:30 **Summary and further course of events**
- 16:30 End of the second preparatory weekend

PubliForum Transplantation Medicine Berne, 24 - 27. November 2000

Friday, 24 November

- 10:00 **Welcoming address**
Dr. Danielle Bütschi, Project-Manager, TA Center
- 10:05 **Inaugural address**
Prof. Heidi Diggelmann, President of the Research Council of the Swiss National Science Foundation
Prof. Thomas Zeltner, Director of the Federal Office for Public Health
Dr. Klaus Hug, President of the Steering Committee of the TA Center
- 10:30 **Citizen Panel's questions on the topic of "Definition of death"**
Answered by
Dr. René Chiolerio, Director of the Intensive Care Unit at the Vaud Cantonal University Hospital
Emilie Hammer, Nurse, Carpediem, Wohn- und Pflegegemeinschaft Stettlen
Vera Kalitzkus, Cultural Anthropologist, University of Göttingen (D)
- 11:30 **Citizen Panel's questions on the topic of "point of view of the persons concerned" (I)**
Answered by
Jürg Blaser, Verein der Eltern von nierenkranken Kindern
Jean-Claude Ruckterstuhl, President of the Association suisse des greffés rein pancreas
- 12:15 Buffet lunch
- 14:00 **Citizen Panel's questions on the topic of "point of view of the persons concerned" (II)**
Answered by
Margrit Kessler, Nurse, President of the Association of Swiss Patients and the Medically Insured
Dr. Hans-Peter Marti, Chief Physician, Berne University Hospital
- 15:00 **Citizen Panel's questions on the topic of "organ allocation"**
Answered by
Trix Heberlein, Member of the Swiss Parliament, President of Swisstransplant
Dr. Eberhard Scheuer, Psychologist, University of Zurich
Prof. Jürg Steiger, Doctor, Hospital Basel
- 16:00 Coffee break
- 16:30 **General discussion between Citizen Panel and Information Persons**

Saturday, 25 November

- 9:00 **Citizen Panel's questions on the topic of "Regulation of donation"**
Answered by
Prof. Didier Houssin, General Director of the Etablissement français des greffes, Paris (F)
Marianne Klug-Arter, Patientenstelle Zürich / Scientific Collaborator, University of Zurich
Marcel Monnier, Lawyer, Federal Office for Public Health
Prof. Denis Müller, Moral philosopher, University of Lausanne
- 10:00 Coffee break
- 10:30 **Citizen Panel's questions on the topic of "Research"**
Answered by
Dr. Robert Rieben, Biologist, Berne University Hospital
PD Dr. Michael Schmoeckel, Doctor, Klinikum Grosshadern, München (D)
Prof. Beat Sitter-Liver, Philosopher, University of Fribourg
- 11:30 **Citizen Panel's questions on the topic of "Xenotransplantation"**
Answered by
Prof. Richard Friedli, Theologian, University of Fribourg
Dr. Bärbel Hüsing, Biologist, Fraunhofer-Institut für Systemtechnik und Innovationsforschung, Karlsruhe (D)
Florianne Koechlin, Biologist, Schweizerische Arbeitsgruppe Gentechnologie
- 12:30 Lunch
- 16:00 **General discussion between Citizen Panel and Information Persons**

Sunday, 26 November

- 9:00 **The Citizen Panel writes the report** (no public access)

Monday, 27 November

10:00 **The Citizen Panel presents its report**

10:30 **Reaction from the audience and discussion**

11:30 **Reactions**

Dr. Andrea Arz de Falco, President of the PubliForum accompanying group

Christine Beerli, President of the Council of States' Commission on Social Security and Health

Rosmarie Dormann, President of the National Council's Commission on Social Security and Health

12:00 **Conclusions drawn by the Organizing Committee**

Dr. Theodor Weber, Federal Office for Public Health

Dr. Beat Butz, Swiss National Science Foundation

Dr. Sergio Bellucci, Center for Technology Assessment

12:30 **Snack and conclusion of the event**

Appendix II

List of Information persons questioned

<i>Name</i>	<i>Organization</i>
Jürg Blaser	Verein der Eltern von nierenkranken Kindern
René Chiolero	Director of the Intensive Care Unit at the Vaud Cantonal University Hospital
Richard Friedli	Theologian, University of Fribourg
Emilie Hammer	Nurse, Carpediem, Wohn- und Pflegegemeinschaft Stettlen
Trix Heberlein	Member of the Swiss Parliament , President of Swisstransplant
Dider Houssin	General Director of the Etablissement français des greffes, Paris (F)
Bärbel Hüsing	Biologist, Fraunhofer-Institut für Systemtechnik und Innovationsforschung, Karlsruhe (D)
Vera Kalitzkus	Cultural Anthropologist, University of Göttingen (D)
Margrit Kessler	Nurse, President of the Association of Swiss Patients and the Medically Insured

<i>Name</i>	<i>Organization</i>
Marianne Klug-Arter	Patientenstelle Zürich / Scientific Collaborator, University of Zurich
Florianne Koechlin	Biologist, Schweizerische Arbeitsgruppe Gentechnologie
Hans-Peter Marti	Chief Physician, Berne University Hospital
Marcel Monnier	Lawyer, Federal Office for Public Health
Denis Müller	Moral philosopher, University of Lausanne
Robert Rieben	Biologist, Berne University Hospital
Jean-Claude Ruckterstuhl	President of the Association suisse des greffés rein pancreas
Eberhard Scheuer	Psychologist, University of Zurich
Michael Schmoeckel	Doctor, Klinikum Grosshadern, München (D)
Beat Sitter-Liver	Philosopher, University of Fribourg
Jürg Steiger	Doctor, Hospital Basel

Appendix III

Secondary and Specialized Literature

The following publications can be ordered from the organizing committee:

Center for Technology Assessment

Inselgasse 1, 3003 Bern; Tel. 031 3232 99 63 Fax. 031/323 36 59
E-Mail: ta@swr.admin.ch

- Egger, U.: Hinweise zur Rolle des Mediators beim PubliForum. Arbeitsdokument, TA-DT 27/2000
- Hüsing, B. et al.: Xenotransplantation. TA 30/1998.
- Hüsing, B. et al.: Xenotransplantation – Tested on Heart and Kidneys. Short version of the TA study "Xenotransplantation". TA 30a/1998.
- Fact Sheets on Transplantation Medicine (distributed to the PubliForum participants, and also accessible by consulting the site: www.publiforum2000.ch)
- Mediendossier über das PubliForum Transplantationsmedizin / Revue de Presse sur le PubliForum "Médecine des transplantations", 2001.
- Pressespiegel über die Transplantationsmedizin / Recueil d'articles de presse sur la médecine des transplantations, 20.11.2000.

Federal Office of Public Health

Law Departement, 3003 Berne; Phone. 031 322 69 98 Fax: 031 322 68 96 (all publications mentioned are available in German, French and Italian)

- Bundesgesetz über die Transplantation von Organen, Geweben und Zellen (Transplantationsgesetz) – Vernehmlassungsentwurf, 1999 (www.admin.ch/bag/transpla/gesetz/d/index.htm).
- Transplantationsgesetz. Erläuternder Bericht zum Vernehmlassungsentwurf, 1999.
- Bericht über die Ergebnisse des Vernehmlassungsverfahrens zum Vorentwurf eines Transplantationsgesetzes, 2000.

Swiss National Science Foundation

Secretary NRP 46: Mrs. U. Seiler, c/o Praxis Dr. Kränzlin, Missionsstr. 24, 4055 Basel
Phone: 078 677 66 71 e-mail: useiler@nfp46.ch

- Transplantationsmedizin: neue Perspektiven, neue Herausforderungen. *BioTeCH forum* 3/00, pp. 85-127.
- NFP 46 "Implantate und Transplantate", *BioWorld* 5-2000, p.38.
- NFP "Implantate und Transplantate" – Programmporträt.
- Bibliographie mit ethischen, rechtlichen, sozialwissenschaftlichen Titeln zur Transplantation.

Appendix IV

Accompanying Group

Andrea Arz de Falco	University of Fribourg, President of the Ethics Commission on Non-human Genetic Technology (President of the accompanying group)
Daniel Candinas	Surgeon, Queen Elizabeth Hospital, Birmingham, UK, Delegate of the Swiss Academy of Medical sciences
Conrad Engler	Interpharma, Member of the executive board
Pierre-Alain Gentil	Member of the Council of States, Canton Jura
Werner Loosli	Honorary president of the “As de Coeur” patients organisation
François Mosimann	Surgeon, Centre hospitalier universitaire vaudois, Swisstransplant delegate
Catherine Nissen-Druey	Basel Hospital, member of the Swiss Science and Technology Council
Kurt Seelmann	Professor at the Faculty of Law, University of Basel
Rosemarie Soldati	Former Member of the Council of States, Canton Solothurn
Verena Soldati	General Secretary of “Basler Appell gegen Gentechnologie“
Thomas Szucs	University Hospital Zurich; Head of the medicinal economy department
Rosmarie Waldner	Freelance journalist, member of the Steering Committee of the Center for Technology Assessment
Theodor Weber	Federal Office of Public Health, Head of the Transplantation department
Bianca Witvliet	Member of the Ethics Commission of the Swiss Professional Association of Nurses

Organizing Committee and Organizing Staff

Sergio Bellucci	Director of the Center for Technology Assessment
Erika Bucheli	Swiss National Science Foundation, Scientific Journalist
Danielle Bütschi	Center for Technology Assessment, PubliForum Project-Manager
Beat Butz	Swiss National Science Foundation, Head of Division IV
Walter Grossenbacher	Center for Technology Assessment, Responsible for Public Relations
Max E. Hauck	PRAC – PR & Communication, Charged with implementing the National Research Program „Implants and Transplants“
Lorenz Hess	Federal Office of Public Health, Head of communication
Françoise Membrez	Center for Technology Assessment, Secretary
Adrian Rüeegsegger	Center for Technology Assessment, Responsible for the field of "Life Sciences"
Katharina Thurnheer	Center for Technology Assessment, Trainee Project PubliForum
Brigitta Walpen	Center for Technology Assessment, Secretary
Renate Zaugg	Federal Office of Public Health, Law Departement
Mediation	
Ulrich Egger	Mediator, Egger, Philips & Partner AG, Zurich
Laurent Salzarulo	Assistant Mediator, Student, Paris