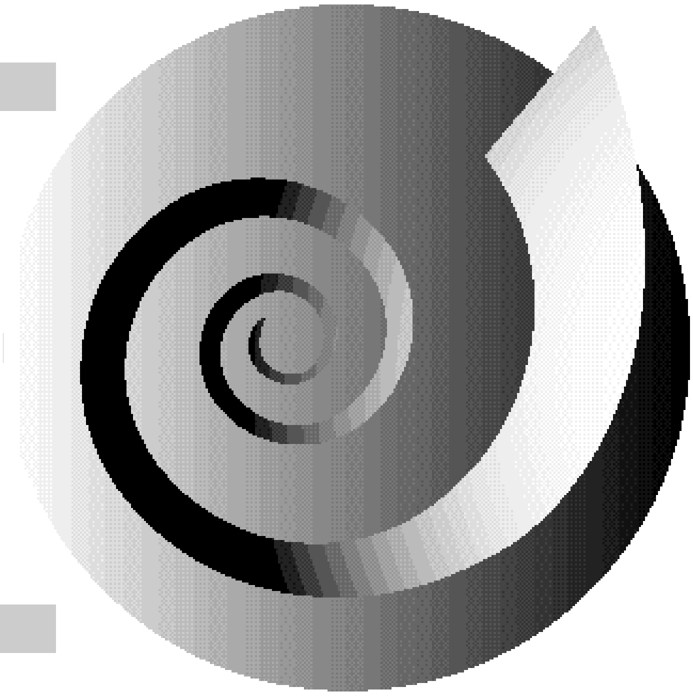
Disabled People Speak on the New Genetics



DPI EUROPE POSITION STATEMENT ON BIOETHICS AND HUMAN RIGHTS

A project funded by the European Commission

DISABLED PEOPLES' INTERNATIONAL · VOX NOSTRA ·

About DPI

Disabled Peoples International (DPI) is a human rights organisation committed to the protection of disabled people's rights and the promotion of their full and equal participation in society. Established in 1981, DPI is represented through active membership of national organisations of disabled people in over 130 countries, including 29 in the European region (DPI Europe).

Background to the project

From pre-natal screening and the selective termination of 'undesirable' pregnancies to euthanasia of disabled adults, one of the biggest threats to the rights of disabled people this Millennium lies within the field of bioethics - the ethics of advances in biological medicine and science. If disabled people's rights are to be protected, it must be in a context where we are confident that society is willing to share burdens and support those whose needs are greater than others to ensure equality of opportunity.

The European disability movement has been working towards this in the context of civil rights but there has been little action in the area of bioethics. Generally, disabled people have been unaware of the fundamental issues and excluded from discussions.

In order to address these issues and to become active, knowledgeable partners, a project on bioethical issues was initiated in accordance with DPI Europe's Action Plan 1999 – 2002, adopted in Syracuse, Italy. One of its priority areas is "… to influence the European Union, Council of Europe and national governments in their way of thinking on bioethical concerns…" and ".. to educate disabled people within Europe and the rest of the world on .. bioethics".

A working group represented by members of DPI Europe in France, Italy, Portugal, Spain and the UK was set up early in 2000 to discuss the issues from a disability perspective and develop the position statement you will find here.

We have consulted with all our European members and they will now embark on a process of disseminating and discussing the information at national level.

Letter from the Chair

The world is changing rapidly. We are witnessing technological revolutions, economic and social transformations, profound modifications in ethics and values. Whilst the ordinary citizen is not consulted or questioned, the consequences of these changes may often profoundly affect the quality of our lives.

The field of biomedicine is one of these areas where profound changes are taking place and which will dramatically affect the lives of disabled people. Disabled people fear that their human rights are once again being threatened and are particularly concerned about the potential for new forms of discrimination inherent in scientific and technical 'progress'. Already discriminated against widely and habitually, disabled people in the European Union, represented by Disabled Peoples International, wish to express their concerns and recommendations loudly and forcefully to society as a whole. To that end, DPI Europe organised the first international conference on Bioethics and Disabled People's Human Rights in Solihull (UK) and embarked on a consultation exercise within its membership to develop a European statement which reflects the concerns and demands of disabled people. This statement, which we hope will form the basis of discussion for an international document to be presented to the United Nations, is the result of a European project funded by the European Commission.

This project has been made possible thanks to the direct participation and input of disabled people from 5 member states; the competence of Bill Albert, Chair of the European Working Group; the commitment of Rachel Hurst, DPI Special Rapporteur, Human Rights; and the coordination work of Julie Marchbank, Project Manager. A special thanks is expressed to Arthur Verney, Development Worker of DPI Europe, who has devoted his energies to carrying out DPI Europe's actions during the past 8 years.

As of today, there will be no debate on bioethics without the voice of disabled people being heard.

Giampiero Griffo, Chair, DPI Europe

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Introduction

> “All Human Beings are born free and equal in Dignity and Rights”
>
> **Universal Declaration of Human Rights, 1948**

Nuclear energy is a source of life and a cause of death. If given an opportunity to express their opinion surely the victims of Nagasaki or Chernobyl would have fought for stricter regulation of the practical use of that new scientific knowledge. The same is true of the revolutionary developments in human genetics.

Many disabled people are only alive today because of scientific progress generally and new medical techniques in particular, so of course we wish to promote and sustain such advances where these lead to benefits for everyone. But we want to see research directed at improving the quality of our lives not denying us the opportunity to live.

The genetic goal of the prevention of disease and impairment by the prevention of lives judged not to be “normal” is a threat to human diversity. It is a potential Nagasaki for everyone, not just disabled people. The threat is powerful and imminent.

Human genetics poses a threat to us because while cures and palliatives are promised, what is actually being offered are genetic tests for characteristics perceived as undesirable. This is not about treating illness or impairment but about eliminating or manipulating foetuses which may not be acceptable for a variety of reasons. These technologies are, therefore, opening the door to a new eugenics which directly threatens our human rights.

- We are threatened when M. Rietdijk, a Dutch physician and philosopher, writes: “A baby should be killed whenever some physical or mental defect is discovered before or after birth.”
- We are threatened when Peter Singer, a professor of bioethics, writes: “It does not seem quite wise to increase any further draining of limited resources by increasing the number of children with impairments.”
- We are threatened when Bob Edwards, a world-famous embryologist, says: “Soon it will be a sin for parents to have a child which carries the heavy burden of genetic disease.”
- We are threatened by selection which leads to the discarding of potentially impaired embryos.

- We are threatened by abortion laws which discriminate against the birth of disabled children.
- We are threatened by the promise of genetic manipulation to eliminate all those differences that non-disabled people consider unacceptable.

This has all happened before. It must not be allowed to happen again.

We want to live as active, equal and productive members of society, but our perceived value and role as well as our human rights are continually diminished by the questionable medical ideas and discriminatory attitudes spawned by the new genetics.

How can we live as equal citizens in society which uses negative images of us to justify the raising of funds for charity and research. This amounts to using disabled people as evidence of the need for our own elimination. We are continually being disabled by such images. How can we live with dignity in societies that spend millions on genetic research to eradicate disease and impairment, but refuse to meet our needs to live dignified and independent lives?

We cannot. We will not.

The genetic threat to us is a threat to everyone. The value of life must not be reduced to a matter of genetic inheritance. If that is allowed to happen no potential child will be safe from arbitrary selection, no parents will escape the moral burden of making impossible choices and no one will be safe from genetic discrimination.

> "Everyone has a right to respect for their dignity...that dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity"
>
> **Universal Declaration on the Human Genome and Human Rights, 1997**

Our experience as disabled people places us in a unique position to contribute to a comprehensive ethical discourse leading to scientific development which respects and affirms the essential diversity of humankind .

Maintaining diversity is as essential for humanity as it is for life as a whole. Our lives as disabled people celebrate the positive power of diversity. Our experience enriches society. These are our unique gifts to the world.

For ourselves, for everyone,
we will not go quietly into the genetic night.

Position Statement & Demands

DPI Europe is greatly concerned about the threat posed to our human rights by developments in human genetics research and practice and by the fact that our voice struggles to be heard in the ethical and scientific debates. In general we have been considered as little more than the passive subjects both of these debates and of genetic research. This has been a profoundly disabling experience.

We are also concerned that the new genetics is fostering a biologically reductive vision of the world which not only undermines what it is to be human but also devalues the importance of social factors, relationships, mutual respect and the environment in determining everyone's quality of life.

> "My guess is that cells will be programmed with synthetic messages within 25 years....The point that deserves special emphasis is that man may be able to program his own cells long before he will be able to assess adequately the long-term consequences of such alterations, long before he will be able to formulate goals, and long before he can resolve the ethical and moral problems which will be raised."
>
> **Marshall Nirenberg, Nobel Laureate, 1967**

Disability, according to the World Health Organisation, is the interaction between people with impairments and environmental barriers, including those of patronising attitudes and images. The new human genetics and cultural and political ideologies which underpin it are working directly against this definition and instead fosters the concept of disabled people as being no more than their impairments. This medicalisation of disability leads to increased discrimination against disabled people and lends support to the massive financial commitment to human genetic research at the expense of tackling the disabling physical and social environment. It is the negative results of the interaction with this environment which disables us, not our impairments, whether they be genetic in origin or, as is the case with the vast majority of disabled people, caused by illness, accident or armed conflict.

We stress that disabled people do not oppose medical research where the object is genuine treatment or the alleviation of pain. What we do oppose is genetic cleansing, driven by profit motive and social efficiency, informed by prejudice against disabled people and carried out in the name of cure or treatment.

Disabled people have faced enforced sterilisation, pre-natal termination, infanticide, euthanasia and wholesale elimination. We were left out on the hills of Sparta to die, sterilised by "caring" doctors in the US, Scandinavia and Germany and were the first to be driven into the Nazi gas-chambers. We testify to the historic and continued links between genetics and eugenics. These links pose dangers for everyone, not just disabled people.

With respect to the impact of genetics on reproduction, we support women's right to choose with respect to their pregnancies. However, we deplore the context in which these choices are made.

- There can be no informed choice as long as genetic counselling is directive and misinforms parents about the experience of disability.
- There can be no free choice as long as the myths, fears, stereotypes of and discrimination against disabled people continues.
- There can be no free choice if women are under social pressure to accept routine tests.
- There can be no real choice until women feel able to continue with a pregnancy knowing that they will be bringing their child into a welcoming society that provides comprehensive systems of support.

We are concerned that the law in most countries discriminates against disabled people by allowing termination of pregnancies after a specified time, if the prospective child might be disabled, yet such discrimination is widely outlawed on the grounds of race and gender. This medicalisation of the quality of life diminishes the value of disabled people's lives and those of everyone.

We are deeply alarmed that without proper social and medical support, disabled people are often made to feel a social burden and are under pressure to choose the option of legalised euthanasia.

We repudiate the utilitarian ideology which informs much of the new human genetics, particularly the assumption that society would be better off without the inconvenience and expense of disabled people. In contrast, we want to see all clinical practice based on strong principles of justice, ethics and non-discrimination with a respect for diversity, autonomy and fully informed choice.

> "... all people have the right to have been conceived, gestated and born without genetic manipulation...."
>
> **Council of Responsible Genetics – Genetic Bill Of Rights - 2000**

DEMANDS

Recognising that advances in human genetics and medical-based quality of life decisions raise serious ethical issues for both disabled and non-disabled people, issues which must be considered within the framework of the essential enduring diversity of humankind;

We demand that:

1. the use of new human genetic discoveries, techniques and practices are strictly regulated to avoid discrimination and protect fully, and in all circumstances, the human rights of disabled people,

2. genetic counselling is non-directive, rights based, widely and freely available and reflects the real experience of disability,

3. parents are not formally or informally pressured to take pre-natal tests or undergo "therapeutic" terminations,

4. all children are welcomed into the world and provided with appropriate levels of social, practical and financial support,

5. human diversity is celebrated and not eliminated by discriminatory assessments of quality of life, which may lead to euthanasia, infanticide and death as a result of non-intervention,

6. organisations of disabled people are represented on all advisory and regulatory bodies dealing with human genetics,

7. legislation is amended to bring an end to discrimination on the grounds of impairment as exceptional legal grounds for abortion,

8. there is a comprehensive program of training for all health and social care professionals from a disability equality perspective,

9. as the human genome is the common property of humanity, no patents are allowed on genetic material,

10. the human rights of disabled people who are unable to consent are not violated through medical interventions.

Basic Genetic Procedures and Concepts

> "The end product of genetic and related research should not be the elimination of disability, but improved information on disability, improved treatment of potentially disabling conditions, and improved support for people with disabilities."
>
> **Inclusion Europe, Reference Document on Bioethics, 1999**

Pre-natal Screening and Testing

Pre-natal screening is carried out on large numbers of pregnant mothers to check on abnormalities in the foetus. This will be done by routine procedures such as ultrasound scanning or a simple blood test.

Pre-natal testing – using the same techniques, is done when the family has a genetic marker or predisposition for a certain condition and the pregnant woman wishes to take the test.

As a result of screening, when the foetus is seen to be 'at risk', testing will then be carried out by use of amniocentesis - the insertion of a needle into the uterine cavity to withdraw fluid for testing for certain conditions, most commonly Downs Syndrome and neural tube defects.

Issues

- Amniocentesis carries a risk of miscarriage – about 1-2%.
- Tests are not always accurate either on verifying whether the condition actually exists or on the degree of severity.
- The underlying reasoning for pre-natal screening and testing is the elimination of impaired foetus. This sends a discriminatory message to say that disabled people's lives are not worth living or worthy of support.
- Counselling before and after testing is often cursory, with expectations that the woman will abort if the test is positive. Counselling should be free, comprehensive and non-discriminatory and should involve disabled people with similar conditions as well as parents.
- Choices of which condition and what level of severity should lead to abortion are made on the basis of myths, fears and stereotypes, not the reality of disabled people's experience.

> "The NDCS does not support the genetic screening of whole populations for genetic conditions, with the consequent risk of moving towards a society in which difference is no longer accepted or tolerated" National Deaf Children's Society (UK)
>
> **NDCS Policy Statement on Genetics and Deafness, 1999**

Pre-implantation Genetic Diagnosis

This is a technique where couples can have their embryos tested for certain impairments before being implanted in the uterus. This allows couples to eliminate the impaired foetus and ensure implantation of a non-impaired foetus. This is now being used for those who are at particular risk of passing on an inherited condition such as Tay Sachs, Duchenne Muscular Dystrophy, Cystic Fibrosis etc. At the moment it is only used through IVF (in vitro fertilisation).

Issues of concern

- Couples who might otherwise not have had a baby, are able to choose a baby which is 'guaranteed' not to have the particular impairment.
- IVF has its own risks and fertility does not always result.
- As further genetic markers are discovered, couples will have more complex choices, which could include physical and personality characteristics as well as impairments.
- As with screening, pre-implantation diagnosis assumes that disabled people are less valuable and that impairment should be avoided. A stereotypical image of the perfect baby is promoted. These assumptions discriminate against disabled people and encourage negative attitudes to our quality of life.
- Again, other people are making assumptions on our quality of life.

> "..people with spina bifida and hydrocephalus live a full life with equal value to that of any other citizen and should not be seen as a medical condition"
>
> **International Federation for Hydrocephalus and Spina Bifida,**
> **Toulouse statement 2000**

Infanticide on the grounds of impairment

This is the killing of a baby who is thought to be so severely disabled that it is not allowed to survive. Death can be caused by use of sedation and cessation of feeding or happen because no attempts are made to clear the airways. Sometimes the justification given is that the baby is not yet a person with attendant rights and that anyway life would be miserable.

In some countries (notably the UK) a mother who is found guilty of infanticide while she is still breast-feeding or shortly after the birth will be found guilty of manslaughter. For anyone else, the killing would be regarded as murder.

Issues of concern

- Sometimes it is felt that as the tests do not necessarily reveal the extent of impairment, it is better to wait until after the child is born before deciding if the child should live. This is, of course, contrary to law and rights which both acknowledge that life starts with the first breath.

- Disabled people's quality of life is measured against medical prediction (not provable facts), economic standards and cultural attitudes. Little recognition is given to the duty of society to support the parents and the disabled child so that the costs and impacts of impairment are diminished and to ensure that the disabled child is welcomed into the human family with the same degree of pleasure as a non-disabled child.

Euthanasia

This is the concept of an 'easy death' – the act of killing someone painlessly, especially to relieve suffering from an incurable and painful illness. There are three types of euthanasia:

- Voluntary euthanasia is at the request of the person who wishes to die,
- Non-voluntary euthanasia is when a person is unable to request it due to physical and/or mental incapacity and the medical profession and the courts of law deem it necessary. An example of this would be the decision to stop feeding and hydrating (giving fluids) to someone who is in a Persistent Vegetative State (PVS)
- Involuntary euthanasia is when someone could have consented or refused but were not asked. For example, the application of Do Not Resuscitate (DNR) notices to elderly or disabled patients' hospital records without their knowledge.

> "..no-one shall be subjected without his free consent to medical or scientific experimentation."
>
> **International Covenant on Civil and Political Rights, 1966**

Issues of Concern

- Supporters of euthanasia argue that voluntary euthanasia is a matter of personal choice without recognising the sometimes very persuasive powers of doctors and relatives who may have subjective reasons for hastening the death of an individual, and the lack of palliative care and support services available to ensure a better quality of life.
- People who are not able to verbally communicate are particular vulnerable to abuse of euthanasia – administered in 'their best interests' but without their informed consent. Research in the Netherlands, the only country to have decriminalised voluntary euthanasia, has shown a significant rise in the death rates of people with intellectual impairments within institutional settings.

> "Limiting the focus to the gene obstructs perception of the multiple facets of the phenomenon of illness"
>
> **Nuremberg Code, IPPNW, 1997**

Genetic determinism

Genetic determinism is the view that we are the sum of our genes, that they predict the impairments and behaviour we will exhibit throughout our lives and that the environment has no real influence.

Issues

- A genetic marker of a particular condition is not the whole story about that gene. A gene is a store of information that determines the sequence of a protein. A specific characteristic arises from the interaction of proteins, cells and tissues and is not just the gene itself. Science still does not know how the whole process works.
- Knowing that you have a marker for a certain condition can ensure that you adopt a lifestyle that will prevent that condition developing.
- The environment has a part to play in what happens to us and is the cause of the majority of disabling impairments – through poverty, accidents, war, environmental hazards etc.
- Genetic determinism has given rise to the opposite theory that so many genes are involved in the development of characteristics that it will be impossible to actually predetermine someone's impairments. This is also a flawed concept, in that research has shown clearly that although there is interaction between genes and how they work, the numbers of genes involved are often small and well within the capacity of modern computer testing.
- Believing that genes are all we are gives emphasis to the idea that impairment and disabled people should be eliminated and removed from the gene pool, ignoring the fact that it may be that nearly everyone will have a genetic flaw of some sort or another. This will give rise to even further delineation between acceptable and unacceptable characteristics.
- The use of genetic information has already led to genetic discrimination in employment and insurance and this problem is likely to increase substantially.

> "No-one shall be subjected to discrimination based on genetic characteristics that ..has the effect of infringing on human rights, fundamental freedoms and human dignity"
>
> **Universal Declaration on the Human Genome and Human Rights, 1997**

Gene Therapy

Gene therapy involves making changes to the gene in order to treat a condition. This could be done by adding a working copy of the faulty gene, by developing genetic-based drug therapy or, as has already been unsuccessfully tried, by imparting a virus into the faulty gene.

There are two kinds of gene therapy:

- Somatic gene therapy - alters the individual gene level.
- Germ line therapy (or human genetic engineering) – alters all the cells in the body, including the reproductive cells and therefore can be passed on through reproduction. This therapy is prohibited in most countries at the moment.

> "An intervention seeking to modify the human genome may only be undertaken for preventative, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants"
>
> **European Convention on Human Rights and Biomedicine, 1997**

Issues

- Although somatic gene therapy and gene-based drugs could be seen as just another form of medicine, there are important ethical concerns around research, consent and experimental treatments, which are arising from the behaviour of scientists and pharmaceutical companies in their bid to win the race and make huge profits.
- Human Genetic engineering raises major questions both about the nature of life itself and the danger of passing on unknown gene combinations to future generations.
- Gene therapies are being publicised as the solution for impairments and research funds are being raised through the portrayal of disabled people as helpless victims of disease. This emphasis on the medical model of disability is further weakening the arguments for funding proper social support for disabled people to live fully and equally in their communities.

> "..genetic invasion into human embryonic development...has serious and incalculable effects for future generations. As such, it is not justifiable"
>
> **Nuremberg Code, IPPNW 1997**

Gene Patenting

This enables commercial enterprises to obtain patents on genetic material when discovered and removed from the body, or on manipulations of genetic material. They can then charge anyone wishing to use that discovery in the process of medical research or drug development. The commercial companies say that this patenting is essential to cover the costs of research. The power of the commercial interests supports the introduction of genetic engineering on plants and animals without adequate research on its consequences on the environment. Although intended to protect scientific invention, the EU has recently issued a Directive on the Legal Protection of Biotechnological Inventions which permits the patenting of discoveries of human genes and gene sequences. This has already had serious cost implications for some national health services, for example in the UK.

Issues

- Patenting maximises profits rather than making treatments available
- Physicians have an ethical obligation not to permit profit motives to influence their free and independent medical judgement. For physicians to pursue, obtain or enforce medical process patents could violate this requirement.
- Treatments will become much more expensive
- Commercial companies will race to obtain the greatest number of patents regardless of research potential
- Disabled people in search of cures have been used by pharmaceutical companies to support patenting in Europe.

> "The human genome in its natural state shall not give rise to financial gains"
>
> **Universal Declaration on the Human Genome and Human Rights, 1997**

Human Genome Project

This project has now sequenced the complete set of chromosomes that humans pass on to their offspring – commonly known as the Book of Life.

The genetic code is now known but what each bit does and how it works is still a mystery. Towards the end of the project it was agreed to put the results on the internet, thus stopping commercial concerns rushing out to patent individual genes.

Issues

- The sequencing of the human genome will change the way we understand ourselves and reinforce the view that we are little more than our genes. Yet they are only part of the puzzle. We have yet to learn about how development and environment influence the way we are.
- Eventually, using the information of the genome, we could eradicate many diseases, ensure longevity and replicate organs as well as design human beings. Being able to make such choices increases the problem of discrimination on the grounds of genetic information and the potential of creating an underclass of genetically imperfect humans.
- Confidentiality of personal genome information will be a serious problem, especially in the areas of health care and insurance.

> "... .we live in an age where although we think of ourselves as scientists and democrats..there is a large residue of pre-science and pre-democracy conceptions and values...a large residue of what our ancestors called barbarism. ...If science of genetics is controlled by barbarians, it will be used to perpetuate barbarism....There doesn't seem to be any divine mandate that we as human beings are going to automatically progress to the promised land."
>
> **Justin Dart, Disabled Activist, 1997**

Instruments related to biotechnology and human rights

- Universal Declaration of Human Rights (1948)
- International Covenant on Civil and Political Rights (1966)
- International Covenant on Economic, Social and Cultural Rights (1966)
- Declaration on the Rights of Mentally Retarded Persons (1971)
- Convention on the Elimination of all Forms of Discrimination Against Women (1979)
- Principles of Medical Ethics relevant to the Role of Health Personnel, particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1982)
- Body of Principles for the Protection of all Persons under any form of Detention or Imprisonment (1988)
- Convention on the Rights of the Child (1989)
- Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1991)
- Declaration on the Elimination of Violence Against Women (1993)
- U.N. Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993)
- WHO Declaration on the Promotion of Patients Rights in Europe (1994)
- European Convention on Human Rights and Biomedicine (1997)
- Nuremberg Code, International Physicians for Social Responsibility (IPPNW) (1997 & 1947)
- Universal Declaration on the Human Genome and Human Rights (1997)
- UNESCO Declaration of the World Conference on Science (1999)
- WHO Guidelines on Medical Genetics and Biotechnology (drafted 1999)
- European Charter of Fundamental Rights (currently being drafted 2000)

- *Breach of a Convention could result in a committee decision to admonish a signatory country.*
- *Declarations can only recommend action to signatory countries.*

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DPI EUROPE POSITION STATEMENT ON BIOETHICS AND HUMAN RIGHTS

I/We support this document. ______ Signed: ________________________________

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