



WORLD HEALTH ORGANIZATION  
ORGANISATION MONDIALE DE LA SANTE

46183

DISTR.: LIMITED  
DISTR.: LIMITEE

WHO/HDP/ICF(M)A/TF/90.4/WP.9  
ENGLISH ONLY

HEREDITARY DISEASES PROGRAMME  
DIVISION OF NONCOMMUNICABLE DISEASES AND HEALTH TECHNOLOGY

Leningrad/Moscow, 26-29 November 1990

JOINT WHO/ICF(M)A TASK FORCE ON CYSTIC FIBROSIS

The perspective of parent/patient associations

by

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#### BACKGROUND

As nations have developed the capacity to diagnose cystic fibrosis (CF), national parent/patient associations have evolved. Each association has evolved in a manner consistent with each nation's culture and in a manner consistent with the social/medical and financial needs of the national CF community.

Typically, associations have been formed, frequently with the encouragement of a clinician, by small groups of parents seeking emotional support and information sharing. In many cases parents have been desperate for an opportunity to discuss their day-to-day problems with others who have lived the same experience. Recognizing they had needs beyond those which could be satisfied in a clinical setting, parents formed groups which ultimately became national associations.

As membership in these groups has grown, the groups have added an external orientation. They have sought to influence the availability and delivery of care related services through, for example, approaches to government for additional funding for care related services. Or, they have approached hospitals or individual practitioners with requests for services more consistent with the needs identified by the parent/patient groups.

Some national associations, in a manner consistent with the customs of their nation, have expanded their activities into fund raising. Funds raised in this way have been directed primarily towards public education programs and to stimulate medical research.

Public education programmes have been both general and specific in nature. At a general level, education programmes have been developed simply to broaden understanding of the disease and empathy for those afflicted. Education

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programmes have also been developed for narrow audiences such as employers, teachers, health care workers, members of the news media and potential contributors.

Other funds have been spent in the direct support of medical research. In this latter capacity, because of their positions as funding agencies, parent/patient associations have had a directive influence on the research conducted. Parent/patient associations have helped scientists focus their research in ways which have proven to be highly productive.

As the life expectancy of those with CF has been extended, distinct patient groups have evolved. Patient groups have typically operated within a framework provided by their national association but with a more narrow, patient-oriented mandate. In one notable exception, the International Association of Cystic Fibrosis Adults has developed into an independent association, albeit funded primarily through the International Cystic Fibrosis (Mucoviscidosis) Association (ICF(M)A) which is in turn funded by member nations. The International Association of Cystic Fibrosis Adults now provides a unique service of a newsletter mailed regularly to CF adults and others in 60 countries.

With the growing strength of many national associations, and with the improving outlook for those with CF, some national associations have begun to assume additional tasks. For example, associations have lobbied governments on issues such as tax policies affecting charitable donations; associations have lobbied governments on issues such as organ donation policies and, more recently, parent/patient associations have begun discussing reproductive technologies.

With this considerable record of achievement, national associations, as representatives of parent and patient interests, clearly have an interest in the new possibilities for prevention and treatment of CF resulting from the gene discovery. It is equally clear, however, that, as with the widely varying clinical manifestations of CF, we can expect widely varying views among nations, and even among members of the CF community within nations, as to the most appropriate future approaches to the disease.

This suggests that there is little likelihood that national associations will ever agree among themselves on the most appropriate response to the ethical questions surrounding prenatal and newborn diagnosis, carrier detection, the provision of genetic counselling and information and genetic therapy. In fact, because of the heterogeneous nature of most national associations, their own members will be unable to achieve nationally acceptable answers to the moral issues raised by these new technologies. In the end, much must be left to individual decision making.

That having been said, however, established parent/patient associations are well equipped to define and articulate the moral perspective(s) of their compatriots. They are also well equipped to help in the design and assessment of pilot projects which almost inevitably will be required as we seek to find the best means of applying the new technologies available to us. In many developing nations of the world, however, mature parent/patient associations do not exist. Nevertheless these new technologies will be as applicable technically in developing nations as anywhere else. It is also the case that additional ethical questions are relevant in developing nations where, for example, the clinical facilities do not exist to respond in an effective manner

to the information which could be made available from application of the new technologies.

All of this suggests that efforts should be made to stimulate development of parent/patient associations in developing nations where they do not now exist.

#### CONCLUSION

Parent/patient associations have contributed much of the momentum and the financial resources, which have led to the improvements in care of those with CF and to the advances in understanding the disease. These associations are now well positioned to articulate the values and customs which will heavily influence the response of the CF constituency in each nation to the new possibilities for the prevention and treatment of CF in light of the gene discovery.

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