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The international charter on prevention of fetal alcohol spectrum disorder

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The first international conference on prevention of fetal alcohol spectrum disorders was held in Edmonton, AB, Canada, on Sept 23–25, 2013. The conference resulted in the production, endorsement, and adoption of the following international charter on the prevention of fetal alcohol spectrum disorder by more than 700 people from 35 countries worldwide, including senior government officials, scholars and policymakers, clinicians and other front-line service providers, parents, families, and indigenous people. It is presented to all concerned in the international community as a call for urgent action to prevent fetal alcohol spectrum disorder.

Fetal alcohol spectrum disorder is a serious health and social problem, as well as an educational and legal issue, which affects individuals, families, and societies worldwide. The disorder is caused by alcohol use during pregnancy—no known amount of alcohol is safe for a growing embryo and fetus, which can develop extensive brain damage and physical abnormalities from exposure to alcohol. Although early intervention and supportive care can improve outcomes for individuals with fetal alcohol spectrum disorder, the associated cognitive, behavioural, and physical impairments can have devastating implications for the individual, family, and other caregivers.¹ Fetal alcohol spectrum disorder is a lifelong disorder.

The cause and consequences of fetal alcohol spectrum disorder have been known for 40 years, yet the disorder continues to afflict millions of people worldwide—about one in every 100 livebirths.² In countries where drinking among women of childbearing age is common, the prevalence of fetal alcohol

spectrum disorder can be substantially higher. This disorder is of overwhelming concern in some populations.³

Fetal alcohol spectrum disorder is preventable. However, one major obstacle to prevention is lack of awareness of the disorder's existence and of risks associated with women drinking alcohol during pregnancy. Opinion-based advice and conflicting messages from different studies about presumed safe amounts of maternal alcohol consumption cause confusion and contribute to a failure to perceive the risk of fetal alcohol spectrum disorder. Findings from basic research have shown clearly that even low to moderate consumption of alcohol can cross the placenta and interfere with the normal development of the embryo and fetus. Heavy or frequent alcohol use increases the risk of giving birth to a baby with fetal alcohol spectrum disorder.⁴

People with fetal alcohol spectrum disorder have additional challenges as a result of their disorder, such as breakdown in family relations, disruption of schooling, unemployment, homelessness, and alcohol and drug misuse.⁵ Adolescents and adults with fetal alcohol spectrum disorder are also at high risk of encounters with the criminal justice system, either as offenders or victims.⁶ Many individuals go to jail and become repeat offenders and are often victimised themselves.⁷ The financial burden of fetal alcohol spectrum disorder on families, communities, and governments is substantial. To address their complex needs, individuals with fetal alcohol spectrum disorder often require additional support in health, social, educational, legal, and correctional services. The associated financial costs are unsustainable for many countries. The cost of people ignoring the problem and not taking action for prevention is going to further increase the strain on scarce societal resources.⁸

Although maternal alcohol consumption during pregnancy is the direct cause of fetal alcohol spectrum disorder, many underlying causes exist for drinking during pregnancy.⁹ Reasons include women having little information about the risks of drinking while pregnant, drinking before pregnancy is recognised, dependence on alcohol, untreated mental health disorders, and social pressures to drink. The complex biological and social determinants of health, including genetics, poverty, malnutrition, and poor social support networks and personal autonomy, also affect drinking behaviour and the severity of its results to the fetus. The risk of alcohol-exposed pregnancy increases with adverse life events, gender-based violence, trauma, stress, and social isolation. Whatever the reasons for women drinking during pregnancy, effective prevention strategies need to be identified and addressed within the social, economic, and cultural context of every community.

The perception that fetal alcohol spectrum disorder is affected only by a woman's choices is a major barrier to effective prevention efforts. Men also have a responsibility. Women's drinking behaviour, and therefore fetal alcohol spectrum disorder, occurs within, and is affected by, a broad familial, cultural, and social context. Partners who show little to no support during pregnancy and who might also misuse alcohol, become violent, and demand that their pregnant partner drink with them, share responsibility for the outcome. Social norms that promote drinking for pregnant women are also responsible for increasing risk of fetal alcohol spectrum disorder. Providers of health care and social services are responsible when they do not inform about the risks of drinking during pregnancy, do not provide meaningful support to help pregnant women to abstain from alcohol, or do not assist families to secure adequate nutrition during crucial times. Alcoholic beverage marketing that targets women of childbearing age without cautioning about the use of the products during pregnancy is also responsible. Society is responsible for failing to help pregnant women to cope with fear, anxiety, violence, malnutrition, and poor health through means other than alcohol use. The risks associated with the underlying determinants of health are a societal challenge.

This charter calls on governments to take action to raise awareness of fetal alcohol spectrum disorder and the risks of alcohol use during pregnancy. Governments must promote a consistent, evidence-based message about prevention by supporting the development and circulation of public health information that is clear and consistent: to abstain from alcohol use during pregnancy is the only certain way to prevent fetal alcohol spectrum disorder. This information must be widely available in every country, responsive to local contexts, and designed to allow access to supportive services for pregnant women. In addition, policies related to the social determinants of health should explicitly address fetal alcohol spectrum disorder; its implications for the individual, family, and society; and how it can be prevented. Access to reliable and affordable contraceptives is an important concern. Prevention of fetal alcohol spectrum disorder should be given a larger role in the development of alcohol policies. The responsibility for prevention of fetal alcohol spectrum disorder should not be placed on women alone. Prevention is a shared duty. Actions should focus on information about the risks of alcohol use during pregnancy, access to reliable contraceptives, and help to deal with addiction and abstinence from alcohol during pregnancy. This support includes provision of timely, compassionate, and competent prenatal care.

Although public knowledge of fetal alcohol spectrum disorder is high in some countries, it is very low worldwide. Assessment of awareness at the population level is an important foundation for making decisions about targeted or general strategies for prevention. Most countries do not have population-level

prevalence data for alcohol use during pregnancy and for fetal alcohol spectrum disorder; in other countries, data are only available for some geographic areas and for specific populations. Research on the incidence and prevalence of fetal alcohol spectrum disorder should be coordinated within and between countries to guide prevention efforts and set benchmarks to measure the success of specific approaches to prevention. Diagnosis of the full range of disorders needs expertise that is not present in most countries. International collaboration in diagnosis of fetal alcohol spectrum disorder should therefore be encouraged as a major step to build diagnostic capacity and link this knowledge to primary and secondary prevention.

Much research on fetal alcohol spectrum disorder is needed. For example, genetic and epigenetic mechanisms that might either facilitate or protect against development are not fully understood. Basic research might lead to the development of methods to more accurately identify high-risk groups and to new opportunities for targeted prevention. For applied research and evaluation, reliable findings are needed from controlled prevention trials of how to reduce the prevalence and incidence of fetal alcohol spectrum disorder. Programmes for prevention must include resources for assessment of their effectiveness. Additional basic and applied research has the potential to increase knowledge about prevalence and of prevention strategies that are truly effective and cost effective.

Several practical and evidence-based methods can be introduced for use in many countries, regions, or communities to help to prevent fetal alcohol spectrum disorder. For example, general information about the disorder can be provided to both girls and boys in appropriate school settings by making use of evidence-based informative materials. Screening for problematic alcohol use in girls and women of childbearing age is also crucial because results might signal a risk of alcohol use in pregnancy. Screening can be done in primary care using already available, validated, and easy-to-use instruments. Evidence-based guidelines for treatment of alcohol abuse in pregnant women are available in published work¹⁰ and on many websites. Informative materials about fetal alcohol spectrum disorder in regionally-specific languages, and that are relevant to local cultures and systems, are needed. Such materials should be made widely available, particularly in schools, clinics, and centres for maternal and child health care. National and international funding agencies and organisations should support such activities, which could be organised in cross-country collaborations.

When more than a million babies are born every year with permanent brain injury from a known and preventable cause, response should be immediate, determined, sustainable, and effective. Broad-based policy initiatives and

actions at different levels of every society are urgently needed to encourage abstinence from alcohol during pregnancy and to prevent fetal alcohol spectrum disorder.

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