



RHTP statement on development and use of prenatal genetic testing and pre-implantation genetic diagnosis

The Reproductive Health Technologies Project (RHTP) has long advocated for the safe, ethical and appropriate development of technologies that women and men can use to promote their reproductive health and wellbeing. RHTP views technology not as an end in itself but as an essential component for all women and men to control their own health and fertility. We believe each technology requires careful analysis of its safety, effectiveness, acceptability, and appropriateness, recognizing that all of these vary from person to person and community to community.

Reproductive genetic tests can give prospective parents more information about the wellbeing of their future children. For some, this information may help alleviate the emotional, financial and physical costs associated with disease. For others, this information may help families better prepare for their role as caretakers of a child with a disability. For others, the information may not seem necessary or relevant. For this reason, the choice to access this information as well as the decisions one might make as a result of the information must remain in the hands of prospective parents and their families.

Reproductive genetic technologies may have unintended consequences or unintended adverse outcomes for individuals and society; some of which may exacerbate social inequities and injustices. To maximize the benefits of such technologies and minimize the risk – both to individuals and society at large – RHTP calls for policy proposals that will ensure the ethical use of prenatal and pre-implantation reproductive genetic tests, improve the safety and accuracy of prenatal and pre-implantation reproductive genetic tests, strengthen clinical service delivery of prenatal and pre-implantation reproductive genetic tests, and provide oversight and enforcement mechanisms.

In establishing such policies, the following goals should be kept in mind:

- Prenatal and pre-implantation reproductive genetic testing should be strictly voluntary.
- Patients should receive genetic counseling which includes complete non-directive information about the patients' options as well as information and local resources that connect patients with individuals who have personal experience with the condition in question.
- Tests should be made clinically available on the basis of clinical evidence which shows the test is safe, accurate and reliable.
- Tests should be made clinically available free from discrimination based on the parent's race, marital status, disability status, sexual orientation or gender.

- Information about reproductive genetic tests and opportunities for such testing should be offered pre-pregnancy with referrals made available for additional screening and testing if desired.
- Standards should be established for health care providers to ensure the safe and ethical use of prenatal and pre-implantation reproductive genetic tests.
- Laboratory facilities that offer reproductive genetic tests should routinely be certified as meeting quality standards.
- Short and long term safety and efficacy data on prenatal and pre-implantation reproductive genetic tests should be collected and made available to the general public on a timely basis and in an appropriate format.
- Socioeconomic and demographic data should also be collected to provide a more complete picture to policymakers about who has access to these technologies and who chooses to use them as well as who does not.
- Public and private insurance coverage for prenatal and pre-implantation genetic testing should be offered only for those tests for which clinical guidelines, preferably across different professional associations, have been established.
- Regulatory guidelines and enforcement mechanisms should apply to all prenatal and pre-implantation genetic tests and facilities whether publicly or privately funded;
- Oversight should be enforced and inappropriate activities should be discontinued and violators subject to penalties.
- Any limits on the use of prenatal or pre-implantation genetic testing should be established only after broad-based public education and consultation which includes people who have used as well as those who have declined to use reproductive genetic tests, health care professionals, researchers, bioethicists, health advocacy organizations, disability and civil rights advocates, parents and prospective parents.

The mission of the Reproductive Health Technologies Project is to advance the ability of every woman of any age to achieve full reproductive freedom with access to the safest, most effective, appropriate and acceptable technologies for ensuring her own health and controlling her fertility. RHTP does not accept any money from biotech or pharmaceutical companies or device manufacturers. Because of the fast-paced nature of reproductive genetic technologies, RHTP will regularly revisit its position on these issues.