

Family Planning via Assisted Reproductive Technologies: Assessing Patient Advocacy Group Perceptions of, Access to, and Utilization of Educational Resources on Reproductive Technologies

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To explore the acceptability, awareness, and current educational practices of rare disease patient advocacy groups (PAG) towards sharing information about family planning and assistive reproductive technologies. Study recruitment was conducted via the Global Genes RARE Foundation Alliance Newsletter, Facebook group, and rare connect platform. Participants who qualified for the study were members of a PAG that represented a rare genetic disease. Participants completed an anonymous online survey that captured their current educational practices and attitudes towards reproductive technologies. In total, 18 PAGs provided information for analysis. Our study indicated that there is a high acceptability and awareness of reproductive technologies by groups who may be amenable to their use. Only 39% of PAGs currently share information about family planning and reproductive technologies, despite our finding that 74% agreed or strongly agreed that PAGs should provide information about these topics. Additionally, 73% of PAGs viewed family health and reproduction as a part of managing their genetic condition and 80% felt that information about preimplantation genetic testing (PGT) would help individuals feel like they had useful choices in managing their condition. Eighty-percent of groups indicated that they would refer patients to genetic counselors to discuss the available options. This was an exploratory study aimed at assessing PAG's current educational practices and attitudes towards ART. We found that the majority of participants agreed that PAGs should share information about family planning, reproductive options, and PGT despite the observation that less than half of the groups currently share information about these topics. Given the acceptability of these technologies, further educational resources need to be developed so that PAGs have accurate and balanced information to share with patients. Genetic counselors have the opportunity to play a key role in sharing resources and educating patient and provider networks about reproductive technologies.