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ORIGINAL ARTICLE

Enhancing recruitment of African-American families into genetic research: lessons learned from Project SuGar

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Abstract Despite some recruitment success in biomedical research among minorities, participation by African-American families into research, specifically genetic research, is lower than Caucasian families (Bowen and Penchaszadeh Community Genet 11:189–190, 2008). Such low participation rates by African-Americans prevent the exploration of specific ethnic differences in patterns of diseases and diminish the identification of specific disease risks among ethnic groups (Bowen and Penchaszadeh Community Genet 11:189–190, 2008). Although African-Americans are heterogeneous, few studies exist to describe effective recruitment strategies across diverse African-American populations, and even fewer studies share effective strategies for the enrollment of African-American families into genetic research. A process evaluation of recruitment strategies used by Project SuGar (a community-based genetic research study focusing on families affected by type 2 diabetes) to enroll African-American families into genetic research was conducted. Our goal was to enroll 400 affected African-American families, and our results yielded 672 families, (n=672). Our success can be attributed to the formation of a Citizen Advisory Committee, recruitment style, flexible protocol, and formal agreement with community health centers. We found that African-American families will participate in research and that providing tangible benefits to the community and utilizing a sense of patience can enhance positive recruitment results. Data from this study may be used to recruit geographically isolated families into genetic research.

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Introduction

The underrepresentation of African-Americans in biomedical research can be attributed to historical, societal, structural, and health care access obstacles (Swanson and Ward 1995). Also, the history of episodic exploitation has contributed significantly to low trust and participation in health-related research (Swanson and Ward 1995; Branson et al. 2007; Royal et al. 2000). A similar barrier as noted by SB Thompson from the University of Pittsburgh is the concept of "cultural memory" which refers to negative feelings arising from remembered sociocultural conflicts (Holtorf 1996). This construct was introduced to the archaeological disciplines by Jan Assmann (Assmann 1988) and used exclusively to denote the collective understandings, or constructions of the distant past, as people hold them within a given social and historical context (Holtorf 1996). Cultural memory also refers to how a group of people with a shared history and cultural identification create ways of perceiving and protecting themselves.

The 1967 Report of the Negro Family ("culture of poverty" and blaming the victim; Moynihan 1967) and *The Bell Curve* in 1994, which used race to justify differences in intelligence (Herrnstein and Murray 1994), also created negative feelings in the African-American population toward research, specifically causing mistrust toward investigators and their interpretation and use of collected data. Thus, it is imperative for any researcher to acknowledge feelings related to cultural memory when approaching ethnic minority groups (Swanson and Ward 1995; Branson et al. 2007; Royal et al. 2000).

Rural and elderly minority populations are considered vulnerable populations who also experience barriers to research recruitment that are economic and structural (Swanson and Ward 1995), causing an unwillingness to participate in biomedical research. Participation in research by such a vulnerable population have been historically low for various reasons, but, most notably, for "the burden of participating in research," which includes the inability to get time off from work, childcare costs, research site access issues, and lack of transportation (Swanson and Ward 1995). Consequently, researchers tend to view vulnerable populations as difficult and too costly, so there is a disincentive on both sides to have African-Americans and other minorities participate in research studies (Swanson and Ward 1995; Herrnstein and Murray 1994).

Background

Genetic risk factors differ across populations, and as such, researchers are challenged to avoid bias in genetic research by the inclusion of minority groups. Moreover, the failure of researchers to enroll subjects across relevant populations may jeopardize study data generalizability, thereby limiting study findings (Bowen and Penchaszadeh 2008; Swanson and Ward 1995; Byrd et al. 2009; Patterson et al. 2008). In fact, diseases that affect patients across ethnic and racial lines require an appreciation for the confounding effects of race, culture, environmental and geographical factors, and ancestral origin (Bowen and Penchaszadeh 2008; Swanson and Ward 1995). Consequently, overlooking these factors may result in negative and ineffective treatment and disparities in health outcomes (Bowen and Penchaszadeh 2008). This knowledge is critical as we move toward genetic equity and applying genetic approaches to modern medicine. It is for these reasons that we need improved methods for engaging disadvantaged minorities into genetic research. Therefore, we need to identify diverse recruitment methods and strategies to increase the participation of African-Americans and other minorities into genetic research because most genetic family studies are conducted among European families (Bowen and Penchaszadeh 2008; Branson et al. 2007).

Our report will address a significant gap in the literature regarding enrolling rural African-American families from the southeast into genetic research.

Overview of Project SuGar

Project SuGar (Sea Island Genetic African-American Registry), the first genetic research study in the Low Country of South Carolina, was designed to better understand the genetics of type 2 diabetes (T2DM) among the Gullahs using a candidate gene approach first, followed by linkage study analysis and a genome-wide association approach. The study, initiated in 1995, is conducted by the Medical University of South Carolina in collaboration with area community health centers and included a research team consisting of PI, nurse manager, ten research nurses, data manager, data entry, lab manager, administrative assistant, and a genetic statistician.

The goal of the study was to create a registry of 400 African-American families affected with T2DM. Specific scientific and community aims were to: (1) ascertain sib pairs and pedigrees with T2DM; (2) collect phenotype information, i.e., anthropometrics, glucose tolerance, lipids, blood pressure, health beliefs/practices; and (3) improve heath services to the community.

Our linkage analysis was completed by the Center for Inherited Disease Research using Illumina's Human Linkage Panel IV b. A total of 521 individuals, including 471 affected subjects and 50 unaffected relatives, were analyzed (Sale et al. 2009). The genotyped population was 76.8% female, obese (median BMI 32.8 kg/m^2), with relatively poor glucose control (median HbA1c 8.8%). Results from the linkage scan in this population revealed a novel locus on the long arm of chromosome 14q and two suggestive loci on chromosome 7. Currently, investigators with Project SuGar are part of a consortium recently funded by NIH/NIDDK to identify genetic risk factors for T2DM utilizing DNA samples from Sea Islanders for a genome-wide association study.

Formation of CAC

Organized in 1995, at the inception of the project, the Citizen Advisory Committee (CAC) comprised 15 community members who represented the faith community, state legislation, community health centers, hospitals, educational establishments, research participants, cultural organizations, and consumers. The CAC continues to meet quarterly at the academic center and free parking and breakfast is sponsored by the project. Over the course of the years, the CAC has adopted the following motto: *We must have patience with our community. Core values: We must acknowledge the fears, health beliefs, and cultural norms of our community and most importantly, the philosophy that research must be service-oriented* (Spruill 2004). Both formal and informal individuals with ties to the community are included, as well as individuals with a science background, to ensure congruence between the research activities and community priorities (Levkoff and Sanchez 2003).

The CAC was instrumental in ensuring cultural competence within the study design and recruitment strategies.

Purpose

There is a lack of published literature describing recruitment strategies among diverse African-American populations and even fewer published studies for enrolling African-American families into genetic research studies (Royal et al. 2000; Byrd et al. 2009; Levkoff and Sanchez 2003; Corbie-Smith et al. 2008; Taylor 2009). We will share our experiences with recruitment to address the gap in the literature regarding strategies for recruiting and enrolling rural African-American families into genetic research studies.

Methods

To determine if we met our project goal and identify effective recruitment strategies, we use process evaluation to answer the following questions:

- Was the strategy recommended by CAC implemented as intended?
- Did these activities lead to the attainment of eligible families?
- Was the program's overall goal of recruiting 400 affected families achieved?
- Which recruitment strategy worked best for our populations?
- What barriers were identified?

To assess whether our strategies were implemented as planned and whether expected output was actually produced, we will discuss and provide a description of our data collection techniques, the recruitment and enrollment process used to recruit families, identification of barriers and our response, and the implementation of effective recruitment strategies.

Data collection

Participants Our data collection consisted of Family Health Questionnaire, (FHQ), clinical assessment, and collection of clinical labs and DNA. We asked the participants a wide array of questions and the FHQ was divided into five parts: All about me, All about my spouse, All about my family, All about my disease, and All about my health. Questions were asked and recorded by the research nurses. Using Coriell computer software, a pedigree was completed on each family enrolled into the study. Each participant was given an opportunity to obtain a free blood glucose meter, and participants without prescriptive coverage were referred to the social worker students for assistance.

Data gathering

Data gathering consisted of reports and recordings from the monthly staff meetings and CAC quarterly meetings.

Staff Throughout the duration of the project, over 100 monthly staff meetings were recorded and held with the research team. The agenda included updates on recruitment activities and outcomes as well as mutual decisions for the most effective recruitment and enrollment practices. Additionally, barriers to recruitment were discussed along with recommendations for most effective strategies. Other topics discussed and shared were how best to recruit sib pairs, indirect recruitment at local health fair events, and identification of training needs of the research nurses and volunteers

Citizen Advisory Committee During the CAC quarterly meetings, the research nurses would present their recruitment activities and the CAC confirmed which strategy yielded the best results. The CAC members also evaluated the progress of the project; recruitment activities/outcomes as well offered additional recommendations for improvements and replications.

Population/sample The sample population consisted of the Sea Islanders or Gullahs of South Carolina. The Sea Islanders or Gullahs are a biologically distinct group of African-Americans living on the coast of South Carolina mostly in the nine counties that make up the Gullah homeland. Commonly accepted counties of the Low Country/ Gullah homeland are Charleston, Berkeley, Dorchester, Colleton, Beaufort, Jasper, Hampton, Allendale, Georgetown, and Horry counties. Recruitment occurred mainly within these counties and the barrier islands of St. Helena, (Beaufort County) John's, James, Wadalamaw, Edisto, Younges of Charleston County, and Pawley Island of Georgetown County.

The Sea Islanders were chosen because they have the lowest European racial admixture of any African-Americans tested in the USA (Pollitzer 1988; Garvey et al. 2003). As direct descendants of enslaved Africans and separated culturally and geographically from the mainland until the 1950s, they developed a distinct Creole language that is still being spoken today (Pollitzer 1988). Additionally, Gullah families were recruited throughout the Low Country in South Carolina because these counties are highly populated (193,034) by African-Americans (US Census Bureau). The families are multi-generational, with close proximity housing, and are closely knitted. Entry and acceptance into the Gullah community is difficult but not impossible.

Recruitment sources/sites Recruitment sources included the Diabetes Registry in Federally Qualified Community Health Centers (FQCHC), Historically Black organizations and clubs, social and civic organizations, local faith communities, and referrals from the Project SuGar CAC.

The nurses also used the informal family "grapevine" to identify the family "gatekeeper."

A description of the recruitment enrollment process

We did not recruit in the first year; instead, we used the first year as our formative and planning stage. We began with the identification of community strengths, plans for community engagement, and hiring of staff to reflect the study population.

Our initial inclusion criteria were strict and included: (1) individuals born or raised on the Sea Islands, (2) sib pairs with type 2 diabetes, (3) self-identification as African-American, (4) having at least one affected biological parent, and (5) having one biological parent still living.

Our study design used active face-to-face contacts with the first affected family member (proband) seeking medical attention or interest in the study. The recruitment process was labor-intensive and consisted of multiple phases. The initial contact was made during the first phase with the proband, and the most important pertinent question asked by the nurse during the initial enrollment process was, "Do you or any of your *blood relatives* have diabetes?" This is very important in African-American families because most African-American families include "fictive kin," individuals who are not related by blood or law but are related by social means via emotionally significant relationships with the characteristics of biological family relationships. Fictive kin frequently function similar to other traditional family members (Farlex 2010).

Usually, this question was followed by "Who is the 'gate keeper' and whom should I approach first?" The first phase established the interest and eligibility of the proband. The second phase consisted of confirming the interest and eligibility of family members, and the third phase consisted of obtaining the informed consent, conducting the interview, and collecting the samples (Fig. 1).

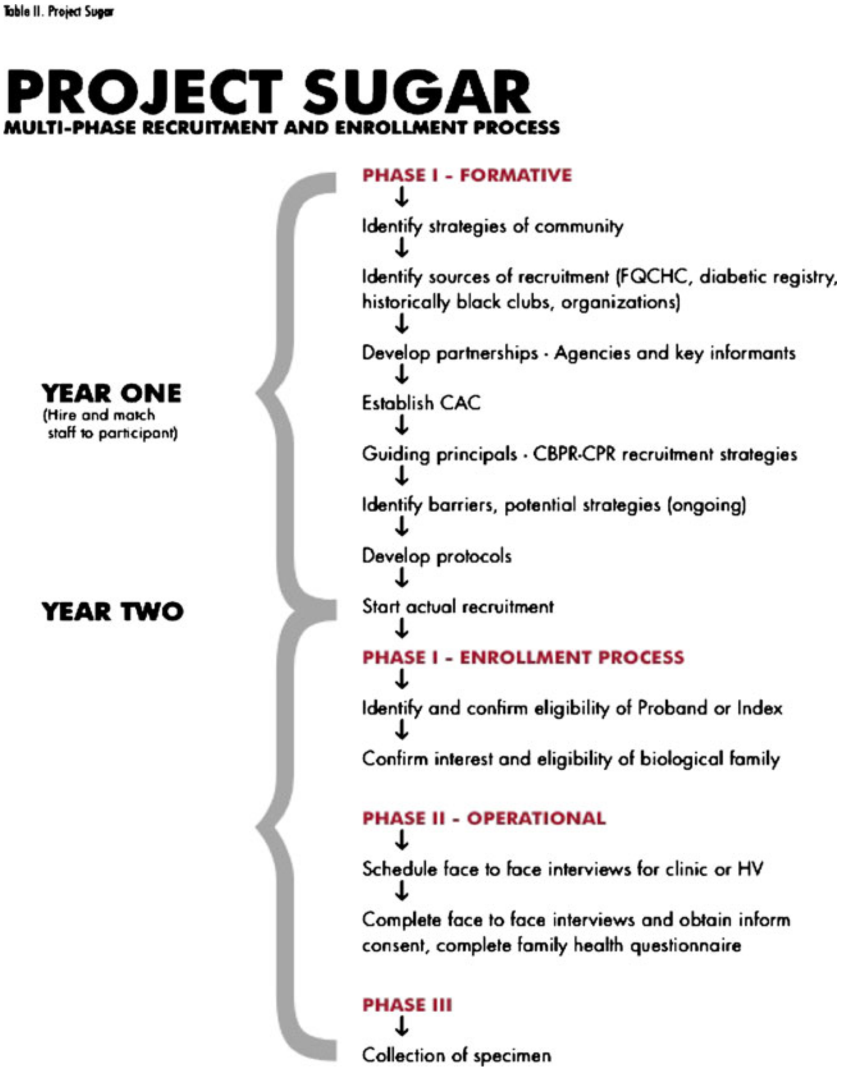

Fig. 1 Project SuGar: multi-phase recruitment and enrollment process

Barriers and strategies We identified and categorized our barriers as follows: (1) study design, (2) structural barrier, and (3) economic barrier. A description of our response and/or strategy to barriers will also be discussed.

Barriers/strategies

Study design

During our monthly and quarterly meetings, we identified inflexible protocol, long questionnaire, fear of research/needle among our participants, and non-traditional family styles. To address the first barrier, the PI amended the protocol and inclusion criteria. This allowed the research nurses to recruit half-siblings and second- and third-generation extended biological family members. Additionally, the protocol was amended to allow recruitment and processing of participants over the weekend and interviews at the work site.

Our strategy to address the fear of participation and completion of the long questionnaire was establishing trust and patience. We began establishing a relationship between the nurse and the participant, which was enhanced by the face-to-face interviews conducted at the community health center. The nurse asked the health questions and recorded all of the health information. Home interviews were optimal to dispel fear, but sometimes during home interviews, the nurses encountered distractions or had difficulty conducting private interviews. Therefore, during home interviews, the nurse would interview family members in a separate room so as to protect confidentiality and privacy of information. For example, during an interview with sisters who had different biological fathers, the oldest sister revealed to the nurses that they did not have the same biological father and was concerned about the inclusion criteria as well as the effect this information may have upon her younger sibling. She was assured that the project adhered to HIPPA Laws and all shared information was confidential. Nonetheless, the majority of the interviews by the research nurses were conducted in the FQCH community health centers.

To address family styles, the nurses distinguished between functional and biological family members by asking questions such as, “who are your blood relatives” and “who are your birth parents?”

During the duration of the project, we encountered participants with poor health literacy skills who were unable to manage their diabetes or understand the importance of HbA1c. We addressed this literacy barrier by educating participants about diabetes self-management during the 90-min blood draw. This interaction was appreciated by the participant and usually resulted in the identification of additional biological blood relatives. We usually completed the informed consent and questionnaire first as this allows time to reduce anxieties regarding the blood draw.

Structural barrier

The social–cultural barriers consisted of a lack of trust toward research and medical institution, cultural memory, and a lack of knowledge toward the local Gullah. Our first strategy to address social–cultural barriers was community engagement, and we spent the first year developing and maintaining a research infrastructure that includes and supports a working CAC. The nurse manager provided leadership and ongoing management of the CAC. The CAC was also instrumental in providing educational lectures on the Gullah culture in that one of the members was a local archivist. Although some of the Project SuGar students and volunteers were from the local community, knowledge of the culture was not assumed because for some, being identified as “Gullah” continues to have a negative connotation. To this end, and according to Sherman Pyatt (local archivist), knowledge of the culture must be reclaimed, and therefore, all volunteers as well as staff had an orientation to the Gullah culture, which required viewing video/documentary *Families by the Sea.*

Other strategies to address these barriers included hiring local nurses who understood and respected the culture. We hired persons to match the cultures and ethnicity of the study participants. This was an important strategy for recruitment and data collection for our population because of culture memory and a history of mistrust, isolation, and racial segregation (Brown 2004; Shavers-Hornaday et al. 1997; Diaz et al. 2008).

Other social–cultural barriers identified by the research team were acknowledging, southern ethics, and social status. The research team displayed professionalism toward the participants and addressed all participants as Ms. or Mr. Additionally, they avoided professional jargon and did not “talk down” to participants. In respect to Southern ethics, during home visits, when participants either offered the research nurse a glass of water, or a seat, it was expected that the nurses would accept the offer of hospitality.

Economic barrier

Economic barriers were identified as missing work to participate in the study, lack of transportation to the research site, and health care availability. One of our strategies for defeating these economic barriers included providing compensation ($50) to the study participants. For transportation issues, the research team would schedule the study at the nearest community health center or a home visit. Additionally, for people with poor access to care, non-federal funds were used to purchase and renovate a recreational vehicle (RV) to serve as a mobile health unit for the study. The RV (the SUGAR bus) provided free screening and education to the Sea Island community. The RV also made appearances at annual cultural events such as the *Gullah Festival*, the *MOJA Arts*

Festival, the *Sea Islands Cultural Arts Festival*, and the *Penn Center Heritage Day.* The mobile health unit provided free diabetes screenings and education as tangible benefits/service to the community. Additional educational services to the community included a quarterly newsletter that provided project updates as well as educational tips for the management of diabetes and a free booklet co-authored by the nurse manager entitled "My Guide to SUGAR."

Role of volunteers Unique to our genetic research study was the ancillary services provided by nursing and social work students. More than 15 African-American and non-African-Americans students (high school and college) completed their clinical practicum placement throughout the duration of the project.

For example, nursing students assisted with community screenings and patients' registration at health fairs, and social work students provided direct services such as referrals to local community resources and assisted in recruiting extended eligible biological family members. We noted a higher yield of recruitment outcomes among the social work students.

Local high school students from YWCA designed poster board on diabetes education for the churches. The Local Department of Social Services "Back to Work" program placed clients with local agencies for work experience, and six clients completed the program with Project SuGar. Although the project was unable to hire clients, we assisted in the preparation for employment by conducting mock employment interviews with the social work students. It is important to note that some of the Back to Work clients had a family history of type 2 diabetes and, as such, were able to recruit biological family members to participate in the research study. Even though the project stopped actively recruiting patients in 2004, the ripple effect of Project SuGar ancillary staffing can still be seen in the local community today as old poster boards are still up in some local churches and the academic institution information line continues to receive calls as well as requests for diabetes screenings from the "SUGAR bus."

Results

The success of a strategy can be measured by whether it is producing an adequate yield of high-risk participants for a project or intervention. Our goal was to recruit 400 affected African-American families, and we successfully enrolled 672 African-American families (N=672).

We attributed reaching our goals to:

1. Community engagement and organization of CAC;
2. Specific tangible benefit to the community, such as free education/screenings and participation in major cultural holidays;
3. Developing a sense of patience with our approach to the community and respect for the culture;
4. Flexible protocol/study design;
5. Innovative use of ancillary and volunteer services; and
6. Recruitment site and sources at FQCHC.

The majority of our enrollment process consisted of active face-to-face interviews at FQCHCs. These personal interactions allowed the nurses to anticipate and address barriers. Additionally, we feel that the face-to-face interviews are important in genetic research because these provide opportunities to explain basic genetic inheritance principles in chronic diseases as well as familiarize African-Americans with recent advances in genomics/genetics services, testing, and research.

Discussion

Principles from community-based participatory research that emphasized community partnerships, and engagement, as well as services to the community were adopted by the CAC. A testimony to the success of the CAC is its longevity and the adoption of recruitment strategies by other researchers to increase the participation of African-Americans into research. For example, a component from our strategies (tangible benefits) is used by the Carolina Center for Biomedical Excellence (COBRE) and Systemic Lupus Erythematosus in Gullahs (SLEIGH) to recruit African-Americans into genetic research. COBRE provides free dental screenings and SLEIGH provides free lupus education.

Specific activities: recruitment site/formal agreement

Our formal partnership with FQCHC consisted of a signed Memorandum of Agreement with ten FQCHC headquarters that included space sharing for each research nurse. For example, research nurses from Project SuGar were placed at these FQCHCs Franklin C. Fetter sites, Beaufort-Jasper-Hampton, St. James Santee, Conway-Georgetown, Waterboro, and Orangeburg-Calhoun sites.

Each FQCHC maintained a diabetes registry, and Project SuGar nurses had access to the registry for the identification of potential families, opportunities to offer free diabetes education, make referral to our social work students, and secure free glucose meter for each research participant.

Procedures/enrollment process

During our formative phase, we used the diabetes registry to mail over 1,000 announcements, and results (<50) indicated that direct mass mailings and "cold calls" did not work well with our population. Instead, non-traditional informal family "grapevine" yielded better outcomes among minority families (Ottman et al. 2005; Hatchet et al. 2000; Ford et al. 2003). A number of studies have posited that when family members are engaged from the onset, subsequent recruitment is easier with family members who have a positive experience. Additionally, the family "grapevine" can help with the recruitment process (Branson et al. 2007; Herrnstein and Murray 1994; Pollitzer 1988; Garvey et al. 2003; Farlex 2010; Ottman et al. 2005; Hatchet et al. 2000).

Our first proband recruited into the study was very non-compliant, but had a positive research experience and in turn convinced three biological siblings to participate. Consequently, one of the siblings was eventually referred to the high-risk, prenatal clinic. Another family member who reported that he never participated in a research study remarked that "being in Project SuGar was the best thing that ever happened to me." We discovered that when recruiting for family association studies, identification of the "gatekeeper," otherwise known as the power broker, is critical because he or she has all the pertinent family information, especially on biological family members (Ottman et al. 2005; Hatchet et al. 2000; Bonvicini 1998).

Our experiences indicate that unlike clinical trials which typically involve individual participants, the biological family is the unit of investigation because it is the fundamental unit concerned with the history and provides conditions for the interaction between environmental factors and biological predispositions to effect expression of genetic traits (Ottman et al. 2005; Hatchet et al. 2000). Consequently, the success of family ascertainment to linkage studies depends on a recruitment enrollment process that acknowledges informal grapevine and the existence of different family styles within African-American families.

Although some may view recruiting families as a research unit a barrier, (Ottman et al. 2005; Hatchet et al. 2000), we did not encounter many families unable to identify eligible blood relatives. We attributed this to our approach to the community, which was slow and respectful as this is important to isolated, vulnerable populations. Additionally, other variables such as the altruism of our participants helped. For example, several Probands remarked that "I am doing this so my grandkids don't have to suffer."

Conclusion

African-American families can be successfully recruited and do participate in genetic research, as evidenced by the Project SuGar research study among the Gullah families of South Carolina. As medical genetics and the study of multifactorial diseases move forward, we must ensure as much as possible that health and genetic benefits are equal. However, this will require continued aggressive recruitment efforts and publication of successful research recruitment strategies across diverse African-American populations. Our report is an attempt to fill a significant gap in the literature regarding enrolling African-American families into genetic research and is similar to the African-American Hereditary Prostate Cancer Study of Royal et al. (2000) in that both reports facilitate the ability of African-American participants to benefit from the improved health outcomes made possible by advances in human genetics.

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