NYU Langone Health

Transplant Institute

APOL1 GENETIC RISK FACTORS ELIMINATES POTENTIAL LIVING KIDNEY DONORS

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Introduction

- Many living donor transplant programs include Apolipoprotein L1 (APOL1) genetic testing to assess risk of CKD in those identifying with African heritage
- In most programs, the presence of two kidney risk variants (KRVs) is an absolute contraindication to living donation
- In an effort to increase **equity in transplant access** for patients with African heritage, our program has implemented a practice change that allows for more thorough assessment of risk factors and shared decision making with patients.

Background

- There are 2 risk alleles associated with APOL1, seen in people with African heritage, that, if present on a person's genotype, could indicate high risk for kidney disease.
- There is still research being conducted on the significance of the risk variants, but we have historically operated with caution and have declined potential donors whose genotypes reflect two risk variants.
- We recently challenged this protocol, encouraging a conversation amongst the team and prompting re-evaluation of the policy to include more stringent requirements for testing.
- Emphasis is placed on including the potential donors in a discussion about the risk, providing them with the most up-to-date research and information, and assisting them in making an informed decision about their option to donate.

Case Profile Prompting Intervention

Requests for second opinion: donors declined at other centers due to presence of 2 KRVs, but were otherwise very healthy

Patients expressed desire to be included in decision making

APOL1 Guideline Development

Transplant Workgroup

- Transplant nephrologists
- Transplant surgeons
- Transplant coordinators
- Research associate with expertise in APOL1
- Medical ethics specialists

Methodology

- Extensive literature review required of all workgroup members
- Conducted over virtual platform allowing participation across campuses from entire group
- Open discussion followed by anonymous survey with results used to drive discussion at follow up meetings
- Practice change monitored for outcomes

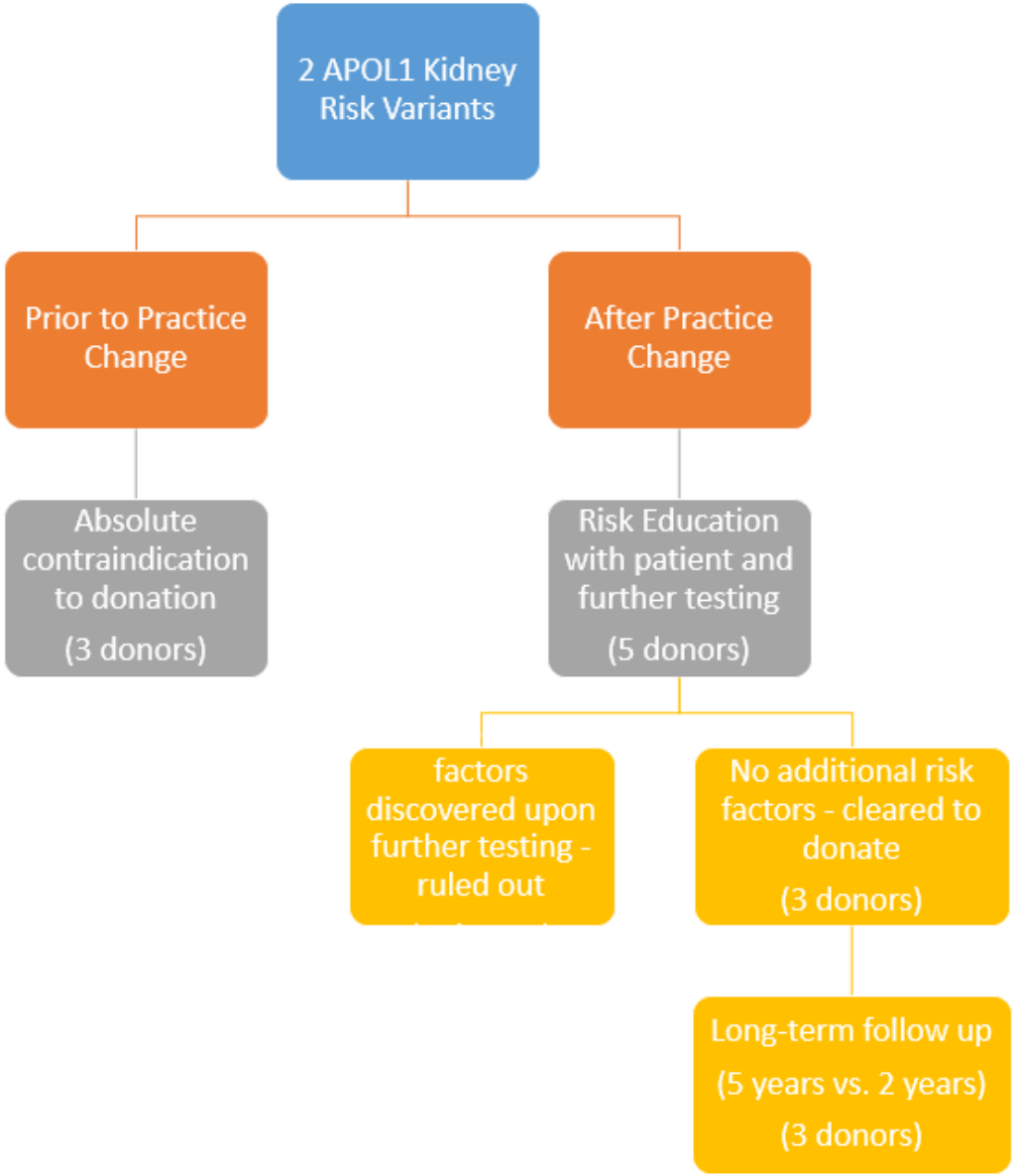
APOL1 Guideline Development

Survey Responses

- Should donors with 2 risk alleles be considered for donation with added testing requirements?
- How frequent should post-donation follow up be? What is our responsibility as the donor team/center if the donor subsequently develops health issues?
- Disclosure – should donors consent to sharing APOL1 results with recipients?

New guidance for decision making re: APOL-1 KRV

RESULTS



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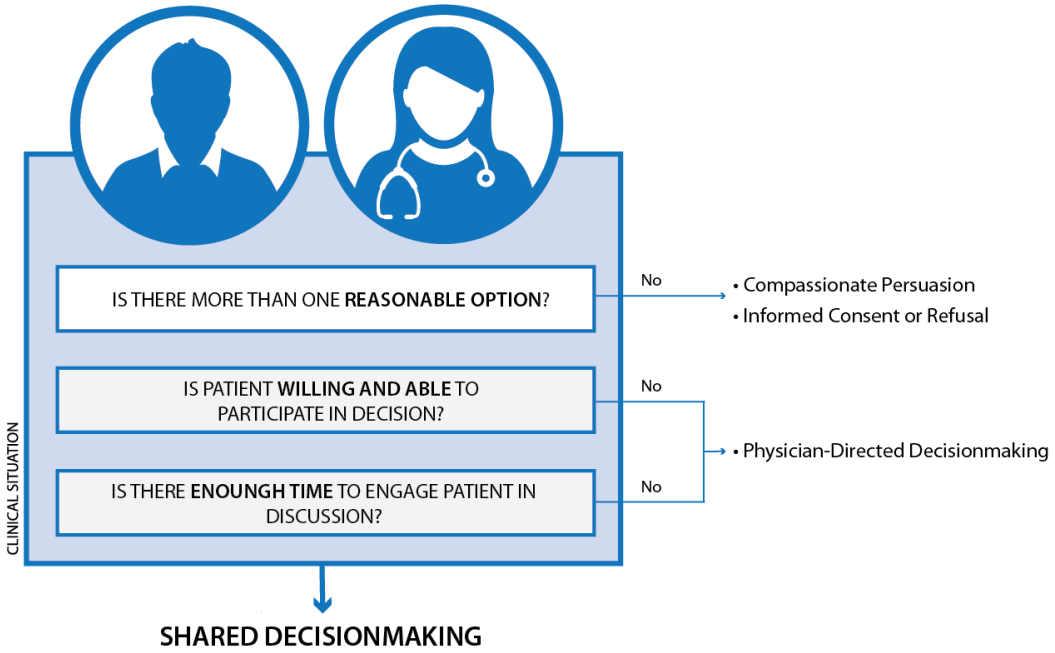
Discussion

Transplant centers should consider examining historical practices that may potentiate the disparities that exist in access to transplantation and living donation.

By implementing a practice of careful testing and supporting engagement in shared decision making, we are able to eliminate one of the potential barriers to donation in patients who identify with African ancestry.



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