

Lisa G. Aspinwall,  
Department of Psychology  
January 24, 2020

## **Research Statement**

My overall research program focuses on the social-cognitive processes involved in representing potential future events and outcomes and, specifically, how people's beliefs about the nature and modifiability of such outcomes are related to actions undertaken to prevent or detect problems early in their course, a process termed proactive coping (Aspinwall & Taylor, 1997). The study of future-oriented thinking, self-regulation, and health affords an opportunity to understand how people may proactively utilize new predictive and diagnostic technologies (such as genetic testing) to manage both potential and actual threats to health. As more conditions are identified for which genetic risk may interact with personal behavior and/or environmental exposure, it becomes increasingly important to understand how people think about these risks, and in particular, whether their own behavior can be effective in reducing disease risk. For risks that are cumulative in nature, promoting proactive risk management earlier in life may reduce the likelihood of disease or may promote detection of disease in its earlier, more treatable stages. Understanding how to optimize these processes earlier in life for interventions targeted to children and families represents an important extension of this work (Wu, Aspinwall, et al., multiple studies; RCT of FLARE intervention, Family Lifestyles, Action, and Risk Education, in progress). Below I describe my work on three different aspects of these questions and future plans to extend this work.

### **Impact of melanoma genetic testing on health cognitions and prevention behavior**

Predictive genetic testing provides the opportunity to learn in advance about the major health risks one is likely to face. Melanoma genetic testing presents an important and highly generalizable model for understanding how people at very highly elevated cancer risk (76% lifetime) think about the role of personal behavior in managing cancer risk. Geographic differences in penetrance suggest that sun exposure superimposes additional risk on members of *CDKN2A* families. This risk is cumulative; therefore, members of these families are counseled to reduce sun exposure. Moreover, early detection is critical – melanomas found at an early stage have a survival rate over 90%, but the survival rate for later-stage disease drops to only 15%. I was fortunate to have the opportunity to design and implement the first prospective study of the impact of melanoma genetic counseling and test reporting on health cognitions, prevention, and screening (Aspinwall et al., 2008, 2009, 2013a, 2013b, 2013c, 2014a, 2014b; Taber et al., 2013) and then to extend this work with an NCI-funded prospective longitudinal study with a novel nonexperimental control group (Taber et al., 2015; Aspinwall et al., 2018, Stump et al., 2019) and a satellite study that involved providing melanoma genetic counseling and testing to minor children ages 10-15 from these high-risk families (Stump et al., 2018; Wu et al., in press).

### **Does genetic testing promote improvements in prevention and screening behavior among adults and children from high-risk families?**

Our initial prospective study, conducted among 60 members of melanoma-prone families who had participated in the gene-discovery phase of research on *CDKN2A/p16*, found that melanoma genetic test reporting promoted sustained improvements in sun-protection and screening behavior over a two-year period without inducing psychological distress or cancer worry (Aspinwall et al., 2013a, 2013c, Aspinwall et al., 2014). We found similar benefits in a later companion study that offered melanoma genetic counseling and testing to minors ages 10-15 from *CDKN2A* families, with similar benefits (Stump et al., 2018; Wu, et al., in press). Although promising, these results could not demonstrate a unique benefit associated with test reporting, as professional ethical

guidelines for genetic counseling require that test reporting must always be accompanied by detailed counseling about familial melanoma risk and its management. Thus, it is difficult to determine whether the risk education provided during genetic counseling may be responsible for the motivational and behavioral benefits we observed following genetic test reporting.

### **Does genetic testing confer benefits over and above the accompanying counseling about risk and its management?**

In the NCI-funded BRIGHT Project (Behavior, Risk Information, Genealogy and Health Trial, R01CA158322-01, \$2.7M, Co-PIs Aspinwall & Leachman, 2011-2018), we compared outcomes of melanoma genetic testing to nearly equivalent counseling based on family history alone in order to evaluate whether there were any unique outcomes resulting from the provision of a genetic test result. We were interested in learning whether genetic test reporting matters (in terms of health cognitions and motivation to perform prevention and screening behavior) to people at highly elevated familial cancer risk, and if so, why? Put differently, if people already know that they are at high risk from their family history, are there any benefits to receiving a genetic test result above and beyond the counseling and education about melanoma prevention that must accompany the test report? BRIGHT used a nonexperimental prospective control group design that compared unaffected family members from families known to carry a *CDKN2A* mutation who underwent genetic testing to unaffected members of families with equivalently strong family history for whom no genetic cause has been identified (and thus no test is available to or appropriate for them). All participants, regardless of family membership, received equivalent counseling regarding genetic risk and identical management recommendations concerning sun protection and screening, but only members of *CDKN2A* families underwent genetic testing.

Our primary findings indicated considerable informational, motivational, and behavioral benefit for genetic testing, compared to the nearly equivalent counseling based on family history received by no-test controls. Specifically, participants who received positive test results indicated that the management recommendations provided during the counseling session were more personally applicable to them (Taber et al., 2015). They reported feeling better informed about how to manage their risk and more motivated to reduce sun exposure (Aspinwall et al., 2018), and they reported both greater perceived risk and greater priority of managing their melanoma risk (Taber et al., 2020). Importantly, although objective measures of UVR dosimetry indicated that both groups reduced daily UVR exposure following counseling, family members who received positive genetic test results were the only group to be less tan on objective assessments of reflectance spectroscopy one year later (Stump et al., 2019). These benefits do not appear to be accompanied by elevated psychological distress or cancer worry.

### **Additional findings from BRIGHT and related experimental studies of how people think about genetic risk in the domains of medicine and law**

Central to my work is an examination of some of the specific health cognitions that may explain when information about genetic risk may either promote or impede prevention behaviors, and when information about genetic causes influences beliefs about future outcomes and their modifiability. Here are a few examples.

- In the domains of both medicine and law, genetic explanations may carry particular weight, motivating acceptance of risk information and corresponding management recommendations (Taber et al., 2015, 2020) and influencing judicial reasoning about responsibility, punishment, and recidivism in complex ways (Aspinwall, Brown, & Tabery, 2012; see also Brown, Tabery, & Aspinwall, 2016).

- In contrast to concerns about genetic determinism inducing fatalism with respect to prevention (a finding that is well documented in laboratory scenario and priming studies), unaffected carriers generally reported increases in perceived control over the development of melanoma and decreased belief that the development of disease was inevitable (Aspinwall et al., 2015, 2020, in prep).
- Loss frames may be especially motivating to people at high risk as they do not wish to lose their opportunity to manage the part of their risk that may be amenable to behavioral control (Taber & Aspinwall, 2015). Our most recent findings from the BRIGHT Project suggest that members of melanoma-prone families who believe that unhealthy behavior will cause their genetic risk to snowball or skyrocket are the most likely to improve sun-protection behaviors one year following melanoma genetic counseling (Aspinwall et al., 2020, in prep).

### **Risk communication and family-focused interventions for at-risk kids**

In collaboration with Yelena Wu, Kim Kaphingst and others, we have developed and implemented several interdisciplinary studies devoted to improving sun-protection behavior and reducing sunburns among children at high familial risk of melanoma (the SPARK, MERIT, and FLARE studies, along with BRIGHT Kids). We have focused on identifying barriers to improved sun-protection among children and examining the impact of storyboard and video risk communications that both illustrate and emphasize the mechanisms through which sun exposure damages the skin and is more dangerous for people with genetic risks than for other people. We are designing and testing family-focused interventions, using risk communication and other intervention materials developed by our team, to improve sun-protection behavior and reduce sunburns among children of melanoma survivors (RCT funded by the American Cancer Society, 2020-2023). As noted above, this work is the culmination of several studies examining barriers to sun-protection behavior in children from melanoma-prone families conducted during the review period, as well as the feasibility and efficacy trial of the intervention and a major review of melanoma prevention interventions (Wu et al., 2016a, 2016b, 2018a, 2018b, 2019, 2020, in press). Importantly, this work extends the study of health cognitions by testing the impact of educational and risk-communication materials that emphasize the mechanism(s) through which sun exposure leads to the development of melanoma on understanding of risk, motivation to reduce risk, and sustained behavior change. Specifically, ultraviolet radiation from the sun damages DNA, this damage is not repaired properly among people with *CDKN2A* mutations, and then new copies are increasingly more damaged, leading to uncontrolled cell growth, resulting in melanoma and other skin cancers. As suggested by Leventhal's common-sense model of self-regulation, risk communications that help people understand *why* their daily behavior poses health risks should be much more influential in motivating sustained behavior change than a general injunction to stay out of the sun.

### **Brief description of current and planned future projects to extend this work**

- **Ongoing analyses of data from BRIGHT focus on examining demographic moderators** (e.g. age, gender, education) of changes in screening following melanoma genetic counseling. Understanding for whom genetic risk communications are more or less motivating is essential to tailoring interventions to support family members in adhering to recommendations for monthly skin self-examinations.
- **Scale development to understand and expand the scope of additive, subtractive, and interactive mental models of genetic risk for disease** and how this risk is influenced by personal behavior and environmental exposure (gene x behavior interactions may influence not just perceived risk of developing disease but also consequential cognitions concerning age of onset, disease severity, and amenability to treatment) – new data collection plus

analysis of 114 detailed structured interviews concerning how people think about familial transmission of both disease risk and protective factors

- **Focus group studies of how people think about new genetic technologies and their intervention implications** (biomarker testing, Taber et al., 2014); epigenetic changes [potential new collaborations, see below)
- **New studies to address health disparities in genetic risk communication:** I am interested in expanding the study of these mental models or sets of health cognitions about genetic risk to underrepresented social and cultural groups. There are glaring SES and ethnic disparities in the study of genetic counseling and testing outcomes, and in the identification of genetic risks and their modifiers, and many reasons to believe that there may be consequential cultural differences in how people think about the relationships among genes, behavior, personal agency, environmental exposure, and health (see Aspinwall et al., 2013c). Understanding these differences is important to ensure the development of risk-counseling protocols and other educational materials that increase the likelihood that the benefits of personalized medicine accrue equally to all groups. As well as to test, rather than assume, whether insights gleaned from the study of affluent and well-educated white participants generalize to families with different cultural beliefs, different experiences seeking medical care, and different resources.
- These extensions and new directions will likely require **new collaborations**, for example,
  - with Liz Conradt, Jim Tabery, and Teneille Brown on how people think about epigenetic changes,
  - with faculty affiliated with the new Center for Genomic Medicine (at which I am giving two presentations in January),
  - with Susan Persky at NCI (epigenetics, genetics and human agency),
  - and/or with researchers and community interventionists from the upcoming national Prevent Cancer Dialogue meeting in April at which I am giving an invited talk and serving as a resource to a community intervention forum on “Community Public Health Messaging about Genetic Testing Related to Cancer.”
- I can also see **extending this work to other health conditions**, such as pediatric asthma, for which genetic risks are being identified that may interact with personal behavior and/or environmental exposure. Our findings with familial melanoma suggest that genetic testing may be especially motivating of sustained changes in daily behavior that need to be enacted consistently to be effective, and the familial and individual changes to personal behavior and environment required to manage asthma triggers likely present similar challenges.