MARION WASSENAAR WITH TANYA MAJOR

Ties That Bind

Gout is a serious health problem in Aotearoa, New Zealand. An increasing number of (mainly) New Zealand Māori and Pacific Island men are affected, with South Auckland now regarded as "the gout capital of the world". Raising awareness of gout's causes and treatment options is essential to reducing the substantial burden it places on patients, their families, and communities in New Zealand. This Art and Genetics collaborative project was an opportunity to engage with the community in a new, creative way and spread the message that gout is a genetic disease that can be treated.

GOUT: THE HISTORY AND SCIENCE

Gout is a form of arthritis caused by a high concentration of urate in the blood. This urate forms tiny, needle-like crystals in the joints, which sporadically trigger an inflammatory response within these joints (known as a gout attack or flare). Gout attacks are so painful that sufferers are often unable to withstand the touch of a single bed sheet on the affected joint, and these attacks can last for several days or weeks. If left untreated, gout can destroy joints and lead to significant disability.²

The patient ... is awakened by a pain which usually seizes the great toe, but sometimes the heel ... or the ankle. The pain resembles that of a dislocated bone ... and ... grows gradually more violent every hour ... the parts affected ... become so exquisitely painful as not to endure the weight of the clothes nor the shaking of the room from a person walking briskly therein.

(Thomas Sydenham, 1683)3

Gout is an ancient disease. The medical notes of Hippocrates (400 BC) described gout as a severely painful disease, which medicine had no hope of curing. His notes also mentioned the tendency for gout to affect only wealthy men, who had access to large amounts of rich food or alcohol, and that attacks often struck after a period of over-indulgence. By the sixteenth century gout had become firmly associated with riches and "high living," (from the Latin: "morbus dominorum et dominus morborum.") and subsequently gout became known as the "disease of lords and lord of diseases," an affliction of the wealthy. In the late eighteenth century and early nineteenth century satirical artworks, depicting a gouty individual proudly displaying their foot upon a footstool, whilst they ate and drank the foods that apparently caused their gouty attacks, became popular (Figure 1).

These satirical artworks mark the beginnings of a shift in attitude toward gout over time, moving away from being viewed as a marker of social status and wealth. The present-day notion of gout (amongst both patients and the general public) commonly reflects the idea that gout is caused by overindulging in food or alcohol, a self-inflicted disease. The term Schadenfreude comes to mind, with the uninformed public appearing to take pleasure in the pain of the gout patient. This perception of gout has led to a common feeling amongst gout patients that they should be ashamed of, or are being blamed for, their condition.

Contrary to the beliefs of the general public gout is an inherited condition, which is primarily caused by a person's genetic make-up. Someone with a family history of gout is twice as likely to develop gout compared to someone with no family history of gout.⁹ Gout researchers today, such as Tanya Major,

are keen to dispel the negative stereotype of gout as a self-inflicted, shameful illness and to raise awareness of the uncontrollable genetic factors that contribute to gout, along with spreading the message that gout is treatable.

The research undertaken by Major and her colleagues in the Merriman Laboratory (Department of Biochemistry) at the University of Otago has come a long way in recent years in identifying the specific genes that are associated with gout and in sharing these findings with gout patients and the general public. At present, Major's research is focused on searching whole-genome (all of a person's genes / DNA) data from over 2,000 Māori / Pacifika people and over 2,000 European people from Aotearoa, New Zealand, to find more genes that influence gout. This genetic analysis technique is called a Genome-Wide Association Study (GWAS). Her aim is to understand how these genes cause gout, and how they might change a person's symptoms or response to treatment, with the goal of improving the lives of people with gout.



Figure 1. E Y Esquire and George Hunt, *An Exquisite Taste, With An Enlarged Understanding*, 1827, aquatint with watercolour; platemark, 25.5 x 37.4 cm. (McLean & Co., London). Sourced from Wellcome Images under the Creative Commons Attribution 4.0 licence.

BEETHOVEN'S NINTH WITH SYMPATHY

In response to Major's research, our initial ideas for producing an artwork for the Art and Genetics exhibition were inspired by Gustav Klimt's *Beethoven Frieze*. Klimt's work was originally presented at the 14th Viennese Secession group exhibition in 1902. Drawn to this work after discovering that Beethoven suffered from gout, the knight in armour appeared in the frieze envisaged as the gout sufferer, who deals with the negative stigma of gout by hiding his affliction behind his armour. The frieze is regarded as a visual representation of Beethoven's Ninth Symphony and consists of three large murals painted directly on the wall and covering three adjoining walls of the exhibition space.

The first wall is said to portray a longing for happiness in a turbulent world where one contends, not only with external hostility, but also with internal weakness. The knight is positioned on this wall with his body in profile, facing the middle wall that depicts antagonistic forces. In positioning the knight as the gout sufferer, this warrior figure faces a tough battle ahead. The gout sufferer must deal with the physical pain and disability of gout attacks, whilst also being confronted with feelings of self-blame and shame for their gout diagnosis, which is reinforced by the lack of understanding from the general public, who see gout as an easily avoidable condition associated with an indulgent lifestyle. The suit of armour offers external protection, yet disguises the emotional, internal pain that affects the gout sufferer and creates a sense of anonymity and distance that may hide their shame.

External and internal conflict, manifesting as the prejudice endured by gout patients with their unspoken and needless humiliation, led to a social and ethical approach to the artwork that engages with the concept of alienation. This is defined as a state of being detached and can refer to how people are excluded or isolated due to barriers in (for example) language, culture, religion, social disposition, sexuality, or political views.13 The familiar is valued, while foreign conditions are treated with suspicion. The negative stigma associated with gout could be seen as a form of alienation elicited through the ridicule and harassment that gout sufferers endure. As Major's research shows and promotes, gout is a genetic disease and does not warrant the negative stereotyping it has long received.

The artwork, *Ties That Bind*, seeks to address the notion of alienation stemming from the lack of understanding about gout, that reflects a sympathetic and personal response to the research. While family



Figure 2. Marion Wassenaar, *Ties That Bind*, 2017, mixed media, four framed works, 34 x 26cm each. Installation view at HD Skinner Annex, Otago Museum, Dunedin.

ties are present within the repeating pattern of clasped hands between parent and child depicted in the background layer, alienation is expressed through repetition, layering, and separation, with the interruption of a crowd scene fractured within the work. Three layers of glass in each of the four framed works provide a surface in which to build up transparent screen-printed images of the crowd and the ominous gouty hand. The crowd scene is able to convey anonymity and the potential for any one of us to inherit the gout genes. Another screen-printed layer on the works illustrates the way large amounts of data are analysed by Major in her quantitative research, through the Genome Wide Association Study (GWAS). Reflective, mirrored surfaces created by the stencil of the gouty hand and the computer hard drives elicit a desire for self-awareness through knowledge and the value of education surrounding scientific research.



Figure 3. Marion Wassenaar, Ties That Bind, detail, 2017, mixed media.

Working with Major on this project has given me a greater understanding of gout and the misconceptions surrounding the disease. However, I could see that what she wanted from this collaboration was an appeal to raise awareness about the genetic link to gout. As such, I wanted to produce giveaway, screenprinted posters to complement my four framed works, *Ties That Bind.* My intention for the posters was to communicate a clear and direct message about the link between gout and genes, and as a giveaway poster, this message would hopefully circulate through a wider audience.

GOUT IS IN YOUR GENES. WHY DON'T WE TALK ABOUT IT ... WHY DON'T WE TALK ABOUT IT!

This collaborative project represented an opportunity to explore the experience of the gout sufferer through art. The use of art as a medium to spark conversation about gout is not a new concept, but this project has

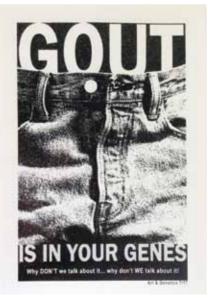


Figure 4. Marion Wassenaar, Gout is in your Genes, 2017, screenprint, 29.7 x 42.0cm. Installation view at HD Skinner Annex, Otago Museum, Dunedin.

allowed the creation of an artwork that inspires sympathy and understanding, where previously satirical artworks have encouraged misconceptions about gout and ridicule of sufferers. The abstraction of the concept of alienation and exclusion within the four framed works of *Ties That Bind* encourages the observer to question their current beliefs and attitudes toward gout, whilst the screen-printed giveaway poster complements the more abstract work with a clear, concise message promoting awareness of the genetic contribution to gout. In our view, this project has achieved the separate aims we each set out to fulfill and produced a thought-provoking work of art.

Tanya Major is a postdoctoral fellow in the Merriman Research Group, studying the genetics of gout and related diseases.

Marion Wassenaar is an artist and lectures in the Print Studio at the Dunedin School of Art.

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