

AMBER

IRISES

Aidan Maartens

Part of

WRITING THE FUTURE

Writing the Future, the world's largest health short story prize, is brought to you by Kaleidoscope Health & Care.

Inspired by science fiction, entries considered how health and healthcare in the UK will look in the year 2100.

The prize was won by Elizabeth Ingram-Wallace with her story 'Opsnizing Dad', and was published along with the five other shortlisted stories in October 2017.

At a time of reflecting on where healthcare has been, a further set of longlisted stories was published in the summer of 2018 to coincide with the NHS's 70th birthday.

All of the published stories are available on the Kaleidoscope website, along with the option to buy a limited edition hard copy of the six shortlisted stories.

Find out more at

kaleidoscope.healthcare/health2100

www.kaleidoscope.healthcare

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About Kaleidoscope Health & Care

Kaleidoscope brings people together to improve health and care.

We find new ways to overcome old barriers. We enable constructive conversations on difficult topics, using inspiring events to encourage clarity of purpose and rigorous problem-solving. Our approach to collaboration is systematic, evidence-based and cost-effective.

Our services enable you to collaborate with rigour. We provide everything required to support effective connections, conversations and networks, from design to management to events. We provide consultancy to help you resolve complex issues through practical, sustainable changes.

As a not-for-profit organisation, we seek to work with our clients in a spirit of kindness, trust, and openness. Our multi-disciplinary team includes clinicians, policy makers, managers, specialists in communication and digital technology, and more.

Could we help you to solve your problems? If so, get in touch, we'd love to hear from you.

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“

**The future is...
a glittering
playground for
quacks and
charlatans**

The girl walked towards the smoke, the only thing that seemed to move in the landscape. As she got closer she saw the fire, and stick figures surrounding it. She crouched behind a fallen tree, close enough to smell the charred air, and heard chants floating through the air. As she tried to make out their meaning, a hand came down softly on her shoulder.

~

– The claimants allege they were misled by DNABLE, both in terms of the probability of successful editing, and the risks of off target hits. In both senses, the resulting child has been adversely affected, in that the targeted regions were not fixed, and that new, unrelated sequences were erroneously edited. This has resulted in an amalgamation of phenotypes: those the parents wished removed or enhanced, which have remained untouched, and those that they could not have prepared for, sprung anew in the child. Of the former, she suffers from far sightedness and needs reading glasses; her blood pressure is above average, and predicted to rise with age; and large effect risk factors for schizophrenia, heart disease and dementia have not been fixed. Of the latter, she is below average height and projected to remain so, in contrast to her tall parents; she is described by them as distant, vacant, unsocial; and, perhaps most appreciably to those in the court today, her skin is of a slightly orange hue, and she has amber irises.

The mother shifted in her chair, switching legs to cross, the father sat motionless. The others in the room – lawyers, reporters, a clerk, a shimmering security guard – turned their faces towards the girl. She was sitting between her parents, looking beyond the judge to the screens on the back wall simulating windows shuttered from the outside, as if they were not in a courthouse but a French farmhouse. The simulation even included the shadows of birds flying by, and watching long enough, she spotted the loop in the sequence. The same screens hung on the walls of the home of her grandmother, who had taken to covering them with bed sheets when the virtual shutters opened every morning to let in a green, bright daytime. As she moved into a seemingly eternal twilight, she had increasingly preferred the dark. The judge, not far from his own twilight, cleared his throat and swallowed what came up.

– Given the predicted impact of her imperfect genome on future health insurance costs, quality of life, earning power, employability, and chances of successful partnering, not to mention the initial outlay, the parents claim that DNable has created a financial burden that will blight their futures, and base their claim on those predicted costs.

The two DNable lawyers, who looked the same man in different suits, smiled in synchrony.

– DNABLE’s response is based on two sections of the contract the claimants signed. Firstly, the section describing unforeseen consequences of genetic editing and their liability therein: the child is demonstrably not suffering from a debilitating disease or disfigurement. The skin tone and eye colour do not count as excessively out of the ordinary, indeed they could be argued to hold a certain attractiveness. The other existing or predicted phenotypes are eminently fixable with current medical and cosmetic techniques. DNABLE thus firmly rejects the claim of liability. Secondly, the parents have waited until the child’s eighth birthday to bring this case. She is clearly outside of the period of warranty, set out in the contract at six years.

The father sat still, the mother’s head now tipped slightly to one side, like a dog’s.

– Nevertheless DNABLE deeply regrets the unforeseen outcome of the procedure. As a gesture of goodwill they are willing to offer the parents a discount on any future editing, and wish the parents to note that, eight years on, the efficiency of the editing regime has increased significantly. The road to human betterment is paved with unsuccessful experiments.

~

- Where did you come from?
- The city, she said, pointing towards the direction she guessed it was.
- How did you get out?
- The gates, the gates were open. Her jaw hung open after the final *n* and when she closed it, it had taken the taste of the fire.
- How? How could they have been open? What happened?
- To this, silence.
- How long have you been out, child?
- I don't know.
- What happened in there?

~

In the car home from the court she sat in the back, her mother opposite her, her father next to her, all staring out of the glass in silence. The questions *what will this mean* and *why did they do this anyway* and *is that what I am* hung in her head like paper mobiles until a gust from an opened door or a startled ghost spun them around and they fell into new arrangements, the words turning into visions, of escaping, of walking away. And then the car stopped: there was something in the road in front of them, a figure, a woman lying on her side. The car shifted its nose side to side, scanning

the body, sending its senses centrally, other vehicles in the area now alerted to the disruption, a team on the way. As it moved gently around her, the girl lifted herself to see as they passed by – the woman's eyes were open, her face puffy and watery. The girl turned back to her mother but the incident seemed not to have registered with her, and she continued looking out as the car sped up.

~

The girl's news of the city caused a stir. Some saw her arrival as an omen beckoning their return (though the youngest of them would never have known it), while others thought all it would bring was more hardship, an outpouring of the sick and the festering of the dead and the inevitable recuperation and retaliation for this incursion of the outside in (for it, whatever it was, had to have come from the outside, on the wind, in the rain, maybe even sent intentionally by those beyond the gates, at least from the eyes of those within). Who knew if we were immune anyway, asked a pessimist, we could just be walking to our own deaths. If we were not immune, countered an optimist, we now would be lying as the girl described those in the city, more liquid than solid, bones softening, for she would have brought it to us, in her breath, on her skin.

~

At home she was ready to return to feigned normality but her parents soon fell apart. She sat in her room with her back to the door and listened to them argue – the cost of the case, it seemed, had drained them, threatening their transplant maintenance payments. They blamed each other for not seeing the folly of the venture, for not reading the contract in the first place. They cried *what are we going to do, we can't afford another one, let alone another edited one*, as argument turned into a shared lament for their misfortune. They must have started drinking – a glass smashed, their voices slurred. And then they went silent. Later in the night the girl managed to find the reporter's report on the case on her console, which was mostly concerned with the fall in the DNABLE share price but did include half a sentence describing her: *the claimants' daughter sat through the hearing unmoved*, which she liked. She learned that hers was one of multiple cases – so there were others like her, with their own disappointed parents; she wondered about the colour of their eyes. Waking in the morning the house was still silent.

~

An old man, previously silent, stood.

– I've been wondering how exactly she is immune to it, when all those around her succumbed?

All eyes fell on her, but her eyes had fallen into the fire.

About the author

I work in scientific publishing, having previously been a research scientist studying developmental biology. I live in Cambridge with my girlfriend and two cats, and have always kept reading and writing alongside my life in science.

Inspiration

I think the potential of genome editing for human traits (particularly ones underlain by complex genetics) can be wildly oversold – I imagined a future where the companies selling such technologies are still full of bullshit, where parents buy into the trap, and where ‘mistakes’ might turn out to be beneficial.

Writing the future

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